INDIVIDUALS' PERCEPTIONS OF END STAGE RENAL DISEASE AND HEMODIALYSIS AND ITS ASSOCIATION WITH ADJUSTMENT AND HEALTH-RELATED QUALITY OF LIFE: A LONGITUDINAL STUDY

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Individuals' Perceptions of End Stage Renal Disease and Hemodialysis and its Association with Adjustment and Health-Related Quality of Life: A Longitudinal Study

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Abstract

A descriptive, correlational study with a repeated measures design was used to monitor changes in individual's perceptions of end stage renal disease (ESRD) and hemodialysis at study entry and at approximately seven months follow-up. A secondary purpose was to examine health-related quality of life (HRQOL) of hemodialysis patients at the follow-up period. Interrelationships among illness and treatment experiences, social supports, adjustment to a new normal, critical events, demographic variables, and medical risk factors were also examined. The Living with End Stage Renal Disease and Hemodialysis (LESRD - H) model was used as the framework for the study.

The non-probability, convenience sample consisted of 60 individuals who were undergoing in-center chronic hemodialysis in the province of Newfoundland and Labrador. The majority of participants were male (51.7%), living with a spouse (60%), and over fifty years of age (68.3%). The mean time on hemodialysis at follow-up was 23.2 months. Most participants had one or more co-morbid illness (61.7%).

Study findings indicated that most participants were generally positive about the illness and treatment experiences, social supports, and adjustment to a new normal at both time periods. Participants were most positive about their social supports and least positive about the illness and treatment experiences at both baseline and follow-up. With the exception of a significant decrease in

satisfaction with support from family and involvement in self-health management, no significant differences were noted in aspects of the illness and treatment experience (i.e., frequency of physiological stressors, performance of activities of daily living [ADL], or confidence with knowledge), social supports (i.e., satisfaction with nurses, physicians, and allied health professional), or adjustment (i.e., emotional well-being and psychosocial distress) between the two time periods.

Study findings related to HRQOL indicated that most participants experienced substantial limitations in physical health, however, they enjoyed excellent mental health. The most problematic areas of functioning were perceived general health, vitality, role functioning limitations due to physical health, and physical functioning.

Select aspects of the illness and treatment experience and social support variables were significantly, and positively, correlated with emotional well-being and psychosocial distress at both baseline and follow-up, however, the relationships were inconsistent between the time periods. Satisfaction with support from family depicted a significant, inverse correlation with psychosocial distress at follow-up. Only select aspects of the illness and treatment experiences (i.e., physiological stressors and performance of ADL) and adjustment (i.e., emotional well-being) were found to influence physical health. None of the social support variables exerted any influence on physical health.

As well, select aspects of the illness and treatment experience, support, and adjustment exerted a significant, positive relationship with mental health. Demographic and medical risk factors exerted variant and minimal effects on adjustment and HRQOL.

The study findings provide limited support for the assumptions inherent in the LESRD-H model. It is postulated that illness and treatment and social support exert a direct effect on adjustment. Counter to model assumptions, several of the illness and treatment and support variables depicted inconsistent relationships with adjustment between baseline and follow-up. As proposed in the model, the direct effects of illness and treatment experiences on physical and mental health is partially support by the study findings. Counter to model assumptions, social support variables exerted no direct effect on physical health, and minimal effect on mental health. The findings provide partial support for the influence of adjustment on HRQOL. Most adjustment variables were found to exert a significant, positive relationship on physical and mental health, with the greatest influence on mental health. Critical events exerted minimal effects on adjustment or HRQOL, however, the correlations were consistent with the assumptions in the model (i.e., better physical and mental health with positive events and worse physical and mental health with negative events).

Although study findings are supported for the most part by previous research, the ability to generalize the findings are limited due to the small sample

size and the inconsistencies noted in relationships between baseline and follow-up. As well, limited comparable research was available for comparison. There is an obvious need for further longitudinal, repeated measures research that can provide a better understanding of how patients on hemodialysis adjust over longer periods of time. Further research using the LESRD - H with a larger, more diverse population has been completed by the research team and the data are currently being analyzed.

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CHAPTER 1

Introduction

End stage renal disease (ESRD) results from the progressive loss of kidney function usually over a period of several years. A patient is considered as having ESRD when deterioration of the glomerular filtration rate is such that renal death occurs and renal replacement therapy (RRT) (i.e., hemodialysis, peritoneal dialysis, or renal transplantation) is required to maintain life (Canadian Institute for Health Information [CIHI], 2001). The most common form of RRT is hemodialysis, a process that involves reliance on an extracorporeal dialyzer (i.e., an artificial kidney).

The number of Canadians requiring RRT has increased dramatically over the years. In 2000, there were 24,921 individuals on RRT, more than double the 1989 figure (CIHI, 2002). While the number of individuals on hemodialysis evidenced a steady increase from 1989 to 1999, those on peritoneal dialysis remained constant between 1989 and 1994 and then evidenced a steady decline to 1999 (CIHI). The declining use of peritoneal dialysis is counter to the projections made by Schaubel, Morrison, Desmeules, Parsons, and Fenton (1998).

The average age for beginning RRT increased from 55 to 61 years between 1989 and 1999, with the most rapid increases occurring in the 75 years and over age group (CIHI, 2002). With the projected increase in the proportion

of individuals over 65 years of age, it is estimated that the majority of ESRD clients will come from the aged and diabetic populations (National Institute of Health [NIH], 1993). Although the treatment of ESRD has been termed a dramatic technical success in terms of prolonging life, adjusting to a new sense of normal and quality of life (QOL) are also important outcomes requiring the attention of health care providers (e.g., DeOreo, 1997; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Parfrey, Vavasour, Henry, Bullock, & Gault, 1988; Kutner, 1994; Meyer et al., 1994, etc.).

Donabedian (1988) defined quality of care as the ability to achieve anticipated outcomes in different situational contexts. Judgements about quality vary depending on indicators of health outcomes (i.e., survival times, QOL, and HRQOL) and influencing factors (i.e., organizational structure of the health care environment, and technical and interpersonal processes involved in giving and receiving care). In order to provide optimal quality care and promote quality outcomes, it is imperative that health care providers develop a greater understanding of individuals' perceptions of illness and treatment experiences, the usefulness of social supports, and a successful adjustment to a new sense of normal. The current study was part of a national study designed by Parfrey and colleagues[1] to test the psychometric properties of the Patient Perceptions of

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[1] The Kidney Foundation of Canada funded a prospective, longitudinal study, *Testing the Patient Perceptions of Hemodialysis Scale (PPHS)*, by Parfrey, Hutchinson, and Way (1999).

Hemodialysis Scale (PPHS). The primary purpose of the current study was to monitor changes in how individuals on hemodialysis perceive their illness and treatment experiences, social supports, and adjustment to a new normal over an average of seven months. A second purpose was to document the HRQOL (i.e., overall physical and mental health) of hemodialysis patients. A final purpose was to examine the interrelationships among illness and treatment experiences, social supports, critical events, demographics, medical risk factors, adjustment to a new normal, and HRQOL.

Background and Rationale

Previous outcomes research with the ESRD population has focused primarily on mortality (DeOreo, 1997; Lowrie & Lew, 1990; Lowrie, Zhu, & Lew, 1998; McClellan, Anson, Birkeli, & Tuttle, 1991) or technical achievement (process) (Barth, 1993; Burrows & Hudson, 1996). It has been argued that focusing on mortality as an outcome indicator alone is insufficient, and more attention needs to be placed on patients' perceptions of the illness and treatment and resulting implications for their overall QOL (Guyatt, Feeny, & Patrick, 1993; Kimmel et al.,1995; Kutner, 1994; Rettig, 1997; Stewart & Ware, 1992).

Despite the developing research base on individuals' experiences with ESRD and hemodialysis, study findings are often a function of diverse theoretical and methodological approaches. Nevertheless, there is some indication that

these individuals experience mild to moderate physiological and psychosocial stressors (e.g., Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988; Curtin, Baltman, Thomas-Hawkins, Walters, & Schatell, 2002; Fuchs & Schreiber, 1988; Gregory et al., 1998; Gurklis & Menke, 1988;1995; Killingworth & Van Den Akker, 1996; Lok, 1996; Parfrey et al., 1989; Welch & Austin, 1999, etc.). Besides stressor severity, study findings indicate that these individuals perceive slight negative illness effects in most life domains (e.g., Kimmel et al., 1995; Kimmel et al., 1996; Patel, Shah, Peterson, & Kimmel, 2002; Sacks, Peterson, & Kimmel, 1990, etc.), and recognize the importance of performing self-care activities and being informed about the illness and treatment (e.g., Gurklis & Menke, 1995; Jones & Preuett, 1996; Kutner, 1987; Gregory et al.; Nagle, 1998). Although only a few studies use longitudinal, prospective designs, the data suggest that individuals' perceptions of stressor severity (Klang & Clyne, 1997; Parfrey et al.; Welch & Austin) and illness intrusiveness (Devins et al., 1990; Kimmel et al., 1998; Kimmel et al., 2000) remain relatively stable over short time periods.

Study findings also suggest that individuals with ESRD perceive family, health care providers, and friends to be important and useful sources of support (e.g., Cormier-Daigle & Stewart, 1997; Christensen et al., 1992; Ferrans, Powers, & Kasch, 1987; Gregory et al., 1998; Gurklis & Menke, 1995; Kimmel et al., 1995; 1996; Kutner, 1987; Siegal, Calsyn, & Cuddihee, 1987; Tell et al., 1995;

Weil, 2000; White & Grenyer, 1999, etc.). Although limited longitudinal data are available, the evidence suggests that satisfaction with overall supports (Kimmel et al., 1998) and dyadic relationships (Kimmel et al., 2000) are relatively stable over short time periods.

The empirical evidence from qualitative studies also suggests that these individuals are constantly having to redefine themselves, and adapt to changes in health states and treatment requirements (Gregory et al., 1998; Kutner 1987; O'Brien, 1983). Despite the use of diverse indicators of adjustment (e.g., distress, well-being, psychosocial maladjustment, etc.) with the hemodialysis population, most study findings are indicative of effective coping (e.g., Baldree et al., 1982; Blake & Courts, 1996; Cormier-Daigle & Stewart, 1997; Gurklis & Menke, 1988; Klang, Bjorvell, & Conqvist, 1996; Lok, 1996, etc), good overall well-being (Parfrey et al., 1989; Keogh & Feehally, 1999), and good psychosocial adjustment (Kimmel et al.,1995; Kimmel et al., 1996; Klang & Clyne, 1997; Lev & Owen, 1998; Sacks et al.; Siegal et al., 1987). There is also some evidence of mild to moderate depression levels (Killingworth & Van Den Akker, 1996; Kimmel et al., 1995; Kimmel et al., 1996; Kovac, Patel, Peterson, & Kimmel, 2002; Patel et al., 2002; Sacks et al., 1990; Walters, Hays, Spritzer, Fridman & Carter, 2002), and adjustment difficulties (Killingworth & Van Den Akker; Walters et al.). Finally, there is some indication that adjustment indicators are relatively stable over short time periods (Kimmel et al., 1998; Klang & Clyne; Lev & Owen; Parfrey et al.).

Study findings suggest that individuals on hemodialysis have substantial limitations in overall physical health, but experience minimal problems with overall mental health (Curtin et al., 2002; DeOreo, 1997; Diaz-Buxo, Lowrie, Lew, Zhang, & Lazarus, 2000; Kutner, Zhang, & McClellen, 2000; Manns et al., 2002; Merkus, 1997; Meyer et al., 1994; Walters et al., 2002). As well, studies focusing on select aspects of physical and mental functioning provide evidence of mild limitations (e.g., Kimmel et al., 1995; Kimmel et al., 1996; Klang & Clyne, 1997; Lev & Owen, 1998; Kovac et al., 2002; Parfrey et al., 1989; Patel et al., 2002; etc.).

Significantly, there is some evidence indicating that illness and treatment experiences and social supports impact adjustment levels in the hemodialysis population. The frequency and severity of physiological and psychosocial stressors have been associated with coping effectiveness (Cormier-Daigle & Stewart, 1997; Gurklis & Menke, 1988; Lok, 1996), psychosocial distress (Devins, Beanlands, Mandin, & Paul, 1997), and emotional well-being (Barrett, Vavasour, Major, & Parfrey, 1990; Devins et al., 1997). As well, illness intrusiveness has been associated with depression (Kimmel et al., 1995; Kimmel et al., 1996; Kimmel et al., 1998; Sacks et al., 1990), psychosocial maladjustment (Kimmel et al., 1995; Kimmel et al., 1996; Sacks et al.), and emotional distress and psychosocial well-being (Devins et al.). In addition, perceptions of overall support systems have been linked to psychosocial

adjustment (e.g., Devins et al.; Killingworth & Van Den Akker, 1996; Kimmel et al., 1995; Kimmel et al., 1996; Seigal et al., 1987). Finally, demographic and medical risk factors have been found to exert minimal effects on adjustment levels (e.g., Klang & Clyne, 1997; Keogh & Feehally, 1999; Kimmel et al., 1995; Kimmel et al., 1996; Siegal et al.; Walters et al., 2002).

Few studies have examined the effects of illness and treatment experiences, social supports, and adjustment to a new normal on HRQOL in the hemodialysis population. Physiological stressors have been associated with overall physical and mental health (Curtin et al., 2002), and subjective physical functioning (Barrett et al., 1990; Lok, 1996). As well, physical activity has been associated with overall physical health (Kutner et al., 2000). Conflicting findings exist on the effects of overall social supports on physical and mental functioning (Kimmel et al., 1996; Patel et al., 2002; Tell et al., 1995). While no studies were identified that examined the relationship between adjustment and overall physical and mental health, depression has been linked with overall physical and mental health (Walters et al., 2002), greater difficulties with activities of daily living (ADL) (Killingworth & Van Den Akker, 1996), and objective physical functioning (Patel et al.). As well, psychosocial maladjustment has been correlated with objective physical functioning (Kimmel et al., 1995; Kimmel et al., 1996). Finally, demographic and medical risks factors have been found to exert minimal effects on physical and mental functioning (Curtin et al.; Diaz-Buxo et al., 2000; Kimmel

et al., 1995; Klang & Clyne, 1997; Kutner et al.; Patel et al.; Tell et al.; Walters et al.).

Given the inconsistent approaches used to assess adjustment and HRQOL, there is an obvious need to reduce the conceptual and operational ambiguities. It is also apparent that more attention needs to be placed on identifying important influencing factors and monitoring the consistency of their effects on adjustment and HRQOL over time.

Problem Statement

There is no cure for ESRD, only treatment options which often generate multiple losses in many different areas of a person's life. Chronic hemodialysis, in particular, is a potential source of negative repercussions for a person's sense of self and overall physical and mental well-being. Despite the growing literature base on these and other outcomes for individuals receiving hemodialysis, findings remain inconclusive. Part of the problem may be attributed to the absence of a sound theoretical model that is capable of capturing in a comprehensive fashion the relationship of illness and treatment experiences, social supports, adjustment to a new normal, and extraneous factors (i.e., demographic, medical risk factors, and critical events) to overall physical and mental health. The proposed study was designed to address this gap with the conceptual model on Living with End-Stage Renal Disease and Hemodialysis

(LESRD-H).

The LESRD-H model evolved from a qualitative, grounded theory study of hemodialysis patients carried out by Gregory (1998). The model identifies three major theoretical constructs (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) that may influence quality outcomes in patients undergoing hemodialysis. Adjustment to a new normal is also treated as an intermediate outcome which mediates the impact of experiences and supports on quality outcome. The proposed relationships among study variables are captured in the research questions. The reader will find a more detailed discussion of the major constructs and the interrelationships among them in the Conceptual Framework section of Chapter 2.

Research Questions

This study was designed to address the following research questions:

1. How do individuals receiving hemodialysis perceive illness and treatment experiences, social supports, and adjustment to a new normal at baseline and follow-up (i.e., an average of 7-months)?
2. Are illness and treatment experiences and social supports significantly related to adjustment to a new normal?
3. How do individuals receiving hemodialysis rate their HRQOL (i.e., overall physical and mental health)?

4. Are illness and treatment experiences, social supports, and adjustment to a new normal significantly related to HRQOL?
5. Are illness and treatment experiences, social supports, adjustment to a new normal, and HRQOL a function of critical events (i.e., negative or positive experience, support, or adjustment events)?
6. Is adjustment to a new normal and HRQOL a function of select demographics (gender, age, and living arrangement) and medical risk factors (i.e., time on dialysis, hospitalizations, number of co-morbid illnesses, hemoglobin, albumin, phosphorus, urea reduction rate, and illness severity)?

CHAPTER 2

Literature Review

The purpose of this review is to examine the literature related to individuals' experiences with ESRD and hemodialysis treatment and quality outcomes. The review is divided into the three major sections. The first section presents a summary of the research findings related to key factors influencing individuals' adjustment to ESRD and hemodialysis treatment. Special consideration is given to the three dominant constructs (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) within the model proposed by Gregory (1998). The second section provides an overview of the literature related to quality outcomes, with particular attention given to aspects of HRQOL. Finally, an overview of the conceptual framework for this study is presented.

Adjustment to ESRD and Hemodialysis

It is well documented in the literature that ESRD and subsequent treatment with RRT adversely affect the physical, social, and psychological well-being of an individual. It is also evident that adjustment to ESRD and hemodialysis is dependent on factors or events that occur along the illness trajectory that may impede or facilitate adjustment. Research studies exploring the subjective experiences of illness and treatment, social supports, and

adjustment to a new normal across the illness trajectory are extensive. The current review will focus primarily on findings related to the hemodialysis population.

Illness and Treatment Experiences

Researchers have used numerous indicators of illness and treatment experiences (e.g., physiological and psychosocial stressors, self-care activities, illness intrusiveness, etc.) with the hemodialysis population. Although several studies have examined the frequency and severity of stressors and illness intrusiveness, self-care practices (i.e., ability to perform activities of daily living and ability and willingness to monitor one's own health) and confidence with illness and treatment knowledge have received little attention. The discussion in this section is focused on the prevalence and severity of physical and psychosocial stressors, use of self-care practices, confidence with illness- and treatment-related knowledge, and perceptions of illness intrusiveness. Finally, factors influencing illness and treatment experiences are discussed.

Physiological and psychosocial stressors. Stressors related to ESRD and treatment regimes have been identified as physiological (e.g., fatigue, cramps, pruritus, etc.) and psychosocial (e.g., fluid limitations, uncertainty about the future, work interference, social interference, role change, etc.) events. Several prospective, cross-sectional and qualitative studies were identified from

the research literature that examined stressor frequency and severity. A number of disease-specific instruments (i.e., Somatic Symptom Distress Scale [SSDS], Dialysis Stress Scale [DSS], Symptom Scale [SS], Stressor Assessment Scale [SAS], original and modified versions of the Hemodialysis Stressor Scale [HSS], Leicester Uraemic Symptom Scale [LUSS], and a symptom survey or checklist) were used in the studies reviewed. Use of generic instruments was also evident (i.e., Health Index [HI]). Good reliability and/or internal consistency was reported for all instruments (Curtin et al., 2002; Fuchs & Schreiber, 1988; Killingworth & Van Den Akker, 1996; Klang & Clyne, 1997; Lev & Owen,1998; Parfrey et al., 1989; Welch & Austin, 1999).

Parfrey et al. (1989) reported on changes in the frequency and severity of physiological symptoms (i.e., fatigue, pruritus, headaches, sleep disturbances, joint pain, muscle cramps, dyspnea, angina, nausea and vomiting, abdominal pain, muscle weakness, and other) in a sample of stable dialysis patients (n = 63) over a one year period. The SS assessed physiological stressors. Composite severity scores ranging from symptom free to extremely severe were constructed. Study findings revealed that most participants experienced mild physiological symptoms at both time periods. A slight, but significant, improvement in symptoms was noted over time.

Klang and Clyne (1997) carried out a prospective study to investigate physiological and psychosocial stressors in hemodialysis patients (n = 18) and

peritoneal dialysis patients (n = 10). Data were collected pre-dialysis and three to nine months after the initiation of dialysis. A symptom checklist was used to collect data on the frequency of physical symptoms (e.g., thirst, dry throat, nausea, dyspnea, etc.). The HI assessed perceived health in terms of fatigue, lack of energy, sleep disturbances, mobility, sense of loneliness, and mood. Study findings at both baseline and follow-up revealed that most participants had a low frequency of disease-specific symptoms and good overall health. No significant difference was noted in symptoms between the two time periods. The most common disease-specific stressors for both time periods were thirst, sleep disturbances, dry throat, and pruritus. The most problematic areas of overall health (i.e., fatigue and lack of energy) increased significantly following the initiation of dialysis. Age, mode of treatment, and gender did not significantly influence any major study variables. Although the sample size was small, the longitudinal design increases the credibility of the results.

Lev and Owen (1998) used a convenience sample to examine changes in physical and psychosocial stressors at three time periods (i.e., baseline, and 4 and 8 months) in individuals on hemodialysis (n = 64, 36, and 28, respectively). Study findings were restricted to the 28 participants who provided data at all three time periods. The SSDS measured common stressors reported by dialysis patients (i.e., muscle cramps, low blood pressure, nausea and vomiting, headaches, dizziness, extremity pain, itching, shivering, back pain, and chest

pain). The DSS assessed stress responses to ESRD and hemodialysis (e.g., physical weakness, fear of blood clots, cramps during dialysis, sexual dysfunction, oscillating health, etc.). Participants reported mild symptom distress and low levels of physical discomfort at all time periods. Symptom distress and stress responses declined slightly over time. The authors acknowledged that the small sample limited the generalizability of study findings.

Welch and Austin (1999) examined the presence of physiological and psychosocial stressors over a three month period in a convenience sample of in-center hemodialysis patients ($N = 103$). Data were presented on a sample of 86 patients who interviewed at both time periods. Consideration was also given to the impact of select demographic variables (i.e., age, race, gender, marital status, and education) and time on hemodialysis on stressor severity. The original HSS was modified (i.e., 2 items eliminated) and an open ended question on treatment-related problems added. The revised HSS assessed select physiological (i.e., fatigue, muscle cramps, pruritus, venipuncture for hemodialysis purposes, nausea and vomiting, and joint stiffness) and psychosocial (i.e., food and fluid limitations, uncertainty regarding the future, work interference, physical activity limitation, body image, hours on hemodialysis, vacation restrictions, dependence on staff and physicians, restriction on social activities, changes in roles and family responsibilities, costs associated with hemodialysis, loss of bodily function, decreased libido, limited clothing style,

transportation problems, hospitalizations, sleep disturbances, fear of being alone, and decreased ability to reproduce) stressors. The findings revealed a slight declining trend in stressor severity over time. The top five stressors at baseline included fluid limitations, length of treatment time, fatigue, role reversal with children, and physical limitations, respectively. At follow-up, the top five were the same, with the exception of the elimination of fatigue and the inclusion of vacation limitations. Participants who were new to dialysis, had more education, or were younger reported more stressors than those who were on dialysis for longer periods, older, and less educated. No significant effects were found for race, gender, or marital status.

In addition to the longitudinal studies, several cross-sectional, descriptive studies were reviewed that investigated the prevalence and severity of physiological and psychosocial stressors in the hemodialysis population. Baldree et al. (1982) investigated the prevalence and severity of illness- and treatment-related stressors in the hemodialysis population ($N = 35$). The HSS was used for data collection. The mean total and subscale scores indicated participants were experiencing moderate stressor severity. The most frequently reported stressors were fluid restrictions, muscle cramps, fatigue, and uncertainty about the future and food restrictions, respectively. No significant difference in physiological or psychosocial stressors was observed. Age, gender, marital status, education, and time on dialysis failed to influence stressor severity.

Bihl et al. (1988) used the HSS to assess stressors in individuals receiving hemodialysis (n = 18). The mean score indicated participants were experiencing mild stressor severity. The top five stressors were fatigue, boredom with hemodialysis routine, physical limitations, length of treatment time, and fluid limitations. No significant difference was observed between physiological or psychosocial stressor scores.

Parfrey et al. (1988) used cross-sectional data from a prospective study to examine the prevalence and severity of physical and psychosocial stressors in a stable population of hemodialysis patients (n = 75). The SS assessed stressors associated with dialysis. In addition to patients' rankings of the most common physical symptoms, data were collected on frequency and duration of dialysis, need for medical intervention, and the degree to which the symptoms interfered with sleep, activity, and QOL. Aggregate severity scores ranging from 0 to 10 were created based on the severity ranking and other clinical features (i.e., prevalence, duration, interference with life domains, and improvement in QOL). Stressors receiving the greatest severity ratings were fatigue, cramps, pruritus, joint pain, and headaches.

Fuchs and Schreiber (1988) examined stressors in individuals on hemodialysis (n = 30). The SAS was modified to include data relevant for the hemodialysis population. The mean scores indicated participants had mild stress. Limitations in physical activities, vacation time and place, and fluid were

identified as the most stressful. Demographics (i.e., age, marital status, employment status, and education) were not found to influence stressor severity or prevalence.

Gurklis and Menke (1988) investigated illness- and treatment-related stressors in individuals on hemodialysis ($N = 68$). The HSS assessed dialysis related stressors. The study findings indicated participants were experiencing mild physiological and psychosocial stressors. In rank order, the five most frequently reported stressors were fatigue, fluid restrictions, food restrictions and limitations in physical activities, and hospital admissions. Participants had a significantly higher physiological than psychosocial score. Time on hemodialysis failed to influence stressor frequency.

Killingworth and Van Den Akker (1996) used the LUSS to assess uraemic symptoms in individuals undergoing hemodialysis ($n = 48$). The LUSS assessed frequency of common stressors associated with dialysis (i.e., pruritus, sleep disturbances, loss of appetite, fatigue, joint pain, poor concentration, impotence, loss of muscle strength, dyspnea, muscle cramps, and restless legs). The findings indicated participants had moderate stressor levels. The five most bothersome stressors were loss of muscle strength, fatigue, joint pain, pruritus, and sleep disturbances.

Lok (1996) also used the HSS to examine stressors in the hemodialysis population ($n = 56$). The mean scores indicated participants were experiencing

mild to moderate stressor severity. The five most frequently reported stressors were physical limitations, decrease in social activities, uncertainty about the future, fatigue, and muscle cramps, respectively. Participants reported significantly more physiological stressors than psychosocial stressors. Greater time on hemodialysis was significantly correlated with greater overall and psychosocial stressor severity.

Curtin et al. (2002) investigated physiological and psychosocial stressors in hemodialysis patients ($N = 307$). The researcher developed a symptom survey to assess the prevalence of illness- and treatment-related stressors in the previous four weeks. The findings indicated that most of the participants reported a lack of energy and tired feelings (90.5% and 90.7%, respectively). The next most frequent stressors were dry mouth/thirst, pruritus, and lack of interest in sex, respectively.

A few qualitative studies were also identified that explored individuals' experiences with illness- and treatment-related stressors. Similar to the findings from quantitative studies using disease specific instruments, participants identified common physiological and psychosocial stressors.

Using a descriptive survey design, Gurklis and Menke (1995) assessed stressors in the hemodialysis population ($N = 129$). An audiotaped structured interview was used for data collection. All data were collapsed into five major themes (physiological and psychosocial stressors, concerns over initiating

hemodialysis, restrictions associated with a chronic illness, and kidney transplant concerns). Although some of the stressors were similar to those described previously (e.g., fatigue, muscle cramps, joint pain, etc.), new stressors were identified. Unwell feelings after hemodialysis and hypotensive episodes during hemodialysis were frequent stressors. Participants indicated that some of the most problematic physiological stressors were related to events they had little control over (i.e., nausea and vomiting following hypotensive episodes, multiple venipuncture attempts by nurses, hospitalizations and surgery related to thrombosed arteriovenous access). The greatest psychosocial concerns were due to the stress of having to come for hemodialysis and the resulting losses (i.e., missed social activities, loss of time spent traveling to the unit and sitting for hours, and time for recovery at home). Concerns about initiating hemodialysis were related to being scared and needing more information. Kidney transplant concerns were related to the uncertainty of whether it would be successful.

Cormier-Daigle and Stewart (1997) asked a group of males on hemodialysis ($N = 30$) to describe the most stressful illness and treatment events that occurred in the previous month. Weakness was identified as the most frequent illness-related stressor. This was followed equivocally by fatigue, sleep disorders, and drug induced cardiac arrhythmias and diabetic coma. Participants also identified several treatment-related stressors (i.e., travel limitations followed equivocally by time management, and fear of surgery, post surgery

complications, and arteriovenous access thrombosis).

Gregory et al. (1998) used a grounded theory design to explore individuals' experiences with hemodialysis ($N = 70$). Open ended questions were used for data collection. Participants indicated they experienced physiological (e.g., fatigue, dyspnea, muscle cramps, pruritus, etc) and psychosocial (e.g., food and fluid restrictions, uncertainty about the future, dependency, role interruptions, etc.) stressors. The most problematic stressors were fatigue, general weakness, physical limitations, hypotension, muscle cramps, and pain and discomfort with needling of the access site.

Faber (2000) used a phenomenological design to gain an understanding of individuals' experiences with ESRD and hemodialysis ($N = 4$). The data suggested that hemodialysis was associated with physiological and psychosocial stressors. Physiological stressors included such things as fatigue, too much interdialytic fluid removal, pruritus, sleep disturbances, and restless legs. Psychosocial stressors were associated with decreases in cognitive functioning, social and travel limitations, limitations in activities of daily living, and physical functioning limitations. Cost was also identified as a stressor.

Self-care and knowledge. The ability to perform self-care activities and having confidence in illness and treatment knowledge are essential for facilitating adjustment to ESRD and hemodialysis. Both can be viewed as promoting independence and autonomy in individuals who rely on machines and health

care providers for well-being and survival. There is, however, a paucity of research on these variables.

Lev and Owen (1998) investigated changes in self-care self-efficacy of individuals with ESRD receiving hemodialysis. Consideration was given to the influence of physical and psychosocial factors over time. The Strategies Used by Patients to Promote Health (SUPPH) was used to assess participants' confidence in implementing strategies they believed would enhance their health (i.e., coping, stress reduction, making decisions, and enjoying life). The authors reported that the SUPPH had good reliability and validity. Participants reported a moderate degree of confidence in their ability to implement self-care self-efficacy strategies at all time periods. Individuals' confidence in using different strategies revealed inconsistencies over time. Although there was evidence of increased confidence in coping and decision making at 4 and 8 months, the findings for stress management and enjoying life were inconsistent over time. Increased coping significantly correlated with increased occurrence of physical stressors at the third time period. Illness severity and stress failed to correlate with any of the self-care strategies at any time period. Demographic (i.e., age, gender, marital status, ethnicity, education level, or occupation) or medical risk factors (e.g., days hospitalized, admission diagnosis, etc.) were not found to influence confidence in self-care self-efficacy strategies.

There were a few qualitative studies identified from the literature reviewed

that examined knowledge and self-care practices in the hemodialysis population. The findings of five studies are summarized below.

Jones and Preuett (1986) used semi-structured interviews with a sample of individuals receiving in-center hemodialysis ($N = 25$) to investigate self-care processes used to cope with stressors related to illness and treatment. Based on comments from participants, the researchers identified four self-care processes. The first, equalizing, involved decision making and the ability to weigh, juggle, and shift when faced with competing demands for time, energy, finances, desires, and requirements. A second process, substituting, involved participants ability to seek alternatives for desires and activities. Withdrawing, a third process, involved avoiding events, people or social activities. The fourth process, guarding, involved active participation in monitoring changing health states, treatment effects, and the care provided by the health care professionals.

Semi-structured interviews were conducted with individuals on varying forms of RRT ($N = 150$) to examine factors which helped them cope with the uncertainty of living with ESRD (Kutner, 1987). Comments from participants indicated that knowledge seeking, involvement in decision making, and developing an understanding of the physiological changes helped facilitate coping with uncertainties and adjusting to new normals. Other activities (i.e., inserting own needles and choosing home dialysis) also contributed to feelings of independence.

Gurklis and Menke (1995) examined how the use of self-care activities by individuals with ESRD receiving hemodialysis facilitated coping with treatment-related stressors. Most participants' comments were indicative of active involvement in the treatment regime and decision making. Participants viewed monitoring their health and treatment and seeking information and support as essential for helping them understand the effects of hemodialysis and following prescribed treatment regimes. As well, participants indicated that they strived to engage in self-care activities that promoted independence and control (e.g., exercising, socializing, housework, college classes, etc.).

Gregory et al. (1998) investigated how individuals with ESRD receiving hemodialysis employed measures to help them understand and accept the illness and treatment. Participants indicated that having knowledge and being aware of the treatment regime and its effects enhanced their coping. Self-care activities were evident in their descriptions of how they monitored the activities of the dialysis staff and their own health states during hemodialysis. There was evidence of a dichotomy between knowing versus doing. While aware of the need to adhere to the prescribed treatment regime, they experienced a great deal of ambivalence (i.e., the degree to which they were willing to follow the restrictions imposed by the illness and treatment).

Nagle (1998) used a hermeneutics design to explore the meaning of technology for individuals ($N = 11$) receiving hemodialysis. Participants'

experiences with technology were seen as a necessary but reluctant partnership with the dialysis machine for survival. This partnership was associated with the need to be informed about the illness and treatment and involved in decision making. Participants were also cognizant of the importance of monitoring their own physical health and well-being, being willing to engage in health promotion activities, and monitoring the activities of health care providers.

Illness intrusiveness. The preceding sections highlighted several potential illness- and treatment-related sources of illness intrusiveness. There is some evidence suggesting that both positive and negative events impact individuals' perceptions of illness intrusiveness (i.e., the extent to which illness and treatment experiences interfere with important life domains). Although only two longitudinal studies were identified from the literature reviewed, there is additional evidence from cross-sectional and qualitative studies. The most commonly used scales were the Illness Effects Questionnaire (IEQ) and the Illness Intrusiveness Rating Scale (IIRS). Both the IEQ and IIRS are reported to have strong reliability and validity. The following discussion highlights study findings on the perceived effects of the illness and treatment experience.

Using a repeated measures design, Devins et al. (1990) examined illness intrusiveness in individuals with ESRD on some form of RRT ($N = 99$), the majority ($n = 54$) of whom were on hemodialysis (in-center or home). The remainder had received renal transplants ($n = 34$) or were on CAPD ($n = 11$).

Data were collected at baseline and six weeks. The IIRS assessed the degree to which the illness and treatment interfere with valued activities in five life domains (i.e., physical well-being and diet, work and finances, marital, sexual, and family relations, recreation and social relations, and other activities, including self and religious expression, and community and civic activities). The findings indicated that participants reported low to moderate illness intrusiveness in all life domains at both baseline and follow-up. Specifically, physical well-being and diet and work and finances were most affected by the illness and treatment, followed by recreation and social relations, marital and family relations, and other activities, respectively. All dialysis groups had greater perceived intrusiveness than the transplant group. The findings indicated that greater numbers of negative stressful life events was significantly correlated with greater overall perceived illness intrusiveness at both baseline and follow-up. Using partial correlations to control for negative life events, greater perceived illness intrusiveness depicted low to moderate significant correlations with greater time commitments, greater uremic symptoms, greater number of co-morbid illnesses, increased fatigue, and greater difficulties with activities of daily living at both baseline and 6 weeks follow-up. Time on dialysis failed to influence perceptions of illness intrusiveness.

Kimmel et al. (1998) and Kimmel et al. (2000) investigated perceived illness effects in the hemodialysis population. The IEQ assessed perceptions of

negative illness effects on personal, family, social, physical functioning, and concerns about illness consequences. Study participants reported slight interference in the various life domains that was stable over a one year period. Kimmel et al. (1998) noted these findings were comparable to the general medical inpatient population, and samples of patients with arthritis and chronic pain. Illness severity and biochemical parameters failed to influence perceptions of illness effects. Finally, greater illness severity was significantly associated with greater perceived illness intrusiveness in females in the Kimmel et al. (2000) study.

Researchers using cross-sectional study designs also used the IEQ to examine illness effects in the dialysis population. Study findings consistently revealed that most participants perceived slight intrusiveness in important life domains (Kimmel et al.,1996; Patel et al., 2002; Sacks et al., 1990). As well, demographics (i.e., gender and age), illness severity, biochemical parameters, and time on dialysis failed to exert any influence on illness intrusiveness. No significant difference in perceived illness intrusiveness was noted between the incident (less than 6 months on dialysis) or prevalent (greater than 6 months on dialysis) populations (Kimmel et al., 1996).

Several qualitative studies were also identified that investigated patients perceptions of illness intrusiveness. A brief summary of these studies is presented below.

White and Grenyer (1999) used a phenomenological design to investigate the impact of dialysis ($N = 44$) on the individual. Study findings revealed that the illness and treatment were seen as interfering with many aspects of normal life. Participants identified restrictions with social activities, vacations, ability to work, and the ability to remain in their own home. Participants also reported negative responses (e.g., anger, denial, etc.) to the restrictions and limitations imposed on them by the illness and treatment. Other qualitative studies also noted that participants' viewed the illness and treatment as interfering with normal lifestyle (i.e., travel, work, and social activities) (Faber, 2000; Gregory et al.,1998; Gurklis & Menke, 1995; Kutner, 1987).

Summary. Despite the rigid treatment regimen for ESRD, most study participants consistently reported experiencing low to moderate stressors, and low to moderate illness intrusiveness. It is important to note that most of the studies reviewed sampled stable patients and, therefore, may not be a fair reflection of the experiences of the total hemodialysis population. There is also some evidence suggesting that the frequency of stressors may impact perceived levels of intrusiveness. While self-care practices and knowledge are considered to be important facilitators of adjustment to the illness and treatment regimes, limited quantitative studies have been conducted in this area. Finally, demographic and medical risk factors were found to exert minimal or variant effects on stressor severity, self-care practices, and perceptions of illness

intrusiveness. More prospective, longitudinal data are needed to obtain a better understanding of the interrelationships among factors comprising the illness and treatment experiences.

Social Support

Social support is believed to be an important factor influencing individuals' perceptions of illness and treatment experiences. The empirical evidence suggests that individuals give relatively high ratings to support received from family and friends, dialysis peers, and health care professionals. The studies in this section address how formal (e.g., physicians and nurses, etc.) and informal (e.g., family and friends, etc.) supports are perceived by individuals with ESRD who are undergoing dialysis. The findings suggest that both informal and formal supports may contribute to different health outcomes. Consideration is also given to factors influencing support.

Perceptions of supports. Several studies were identified that examined how individuals with ESRD receiving hemodialysis perceived their social supports. Several diverse instruments were identified that assess informal (i.e., The Family Relationship Index [FRI] of the Family Environment Scale [FES], Interpersonal Relationship Index [IPRI], Dyadic Adjustment Scale [DAS]), and formal (i.e., Satisfaction with Care Questionnaire [SCQ], Patient Satisfaction Questionnaire [PSQ]) supports independently. Additional instruments were

identified that assessed both formal and informal supports (i.e., Multidimensional Scale of Perceived Social Support [MSPSS]), Interpersonal Support Evaluation List [ISEL], and Lubben Social Network Scale [LSNS]). The instruments were reported to have good reliability and/or internal consistency (Christensen et al., 1992; Cormier-Daigle & Stewart, 1997; Ferrans et al.,1987; Kimmel et al., 1998; Kimmel et al., 2000; Kovac et al., 2002; Tell et al., 1995). Most of the research was of a cross-sectional nature, with a limited number of longitudinal and qualitative studies.

Kimmel et al. (1998) assessed social support in a sample of individuals receiving hemodialysis. The MSPSS was used to collect data across three time periods (i.e., baseline, 6 months, and 1 year). The MSPSS assessed the perceived supportiveness of family, friends, and special persons. Participants gave high ratings to their overall supports. Support ratings were stable over time. The researchers noted that these findings were similar to those obtained from normative samples of university students. Age and select biochemical parameters (i.e., dialysis adequacy and albumin) failed to influence perceived social support.

In a follow-up study of individuals involved in stable dyadic relationships (i.e., greater than 6 months), Kimmel et al. (2000) reported on overall satisfaction with supports and satisfaction with relationships over time. The MSPSS and the DAS measured overall satisfaction with supports and relationships, respectively.

An overall DAS score and two subscale scores (i.e., DAS negativity and DAS positivity) were computed. Participants were very satisfied with their overall supports and dyadic relationships at all three time periods, with study findings similar to population norms and those for married individuals. DAS negativity and DAS positivity scores were stable over time. Although no significant differences were observed in overall dyadic satisfaction and positivity scores between the genders, females reported greater dyadic conflict than males. As well, older males reported less dyadic conflict than females. Finally, greater overall social support was significantly correlated with greater dyadic satisfaction for both genders, but only females evidenced a strong correlation between greater overall support and lower dyadic conflict.

Cross-sectional studies provided data on how the hemodialysis population perceived social support networks. Findings from select studies are presented below.

Ferrans et al. (1987) examined how satisfied individuals receiving hemodialysis ($N = 416$) were with their health care. The SCQ assessed satisfaction with physicians (i.e., interpersonal skills and professional competence), nursing care/dialysis treatment (i.e., nurses interpersonal skills, professional and technical skills, and dialysis treatment management; and conduciveness of the dialysis environment), and treatment and financial costs. The findings indicated that most participants were very satisfied with the overall

level of care. In order of priority, participants were most satisfied with physicians, nursing care/dialysis treatment, and the costs associated with treatment and transportation. Greater education levels and longer time on dialysis were significantly correlated with lower levels of satisfaction with care. Age, gender, marital status, employment, presence of diabetes, income, and race were not found to influence satisfaction levels.

Seigal et al. (1987) examined the social support systems of individuals receiving hemodialysis ($N = 101$). Qualitative and quantitative data were collected. A researcher developed instrument assessed frequency of contact with informal (i.e., family, friends, fellow workers, and confidants) and formal (health care providers, and religious and volunteer organizations) supports. Family, health care providers, and friends were identified as the most important sources of support by most participants. With regard to the informal support system, friends and family, fellow workers, and confidants were perceived to be quite helpful. Finally, with regard to formal support systems, most participants indicated that members of the medical team were very helpful, and religious and volunteer organizations were the least helpful.

Christensen et al. (1992) examined the perceived supportiveness of the family environment in a sample of individuals receiving in-centre and home hemodialysis ($N = 81$). The FRI was used to measure family support. The FRI comprised three subscales that assess cohesion (i.e., the degree to which family

members are helpful and supportive of each other), expressiveness (i.e., the extent to which family members are encouraged to act openly and to express their feelings), and conflict (i.e., the extent to which open expression of anger and conflict are characteristic of the family). The findings indicated that participants perceived their family environments to be very supportive. None of the demographic (i.e., age, gender, and marital status) or medical risk factors (i.e., diabetes, time on dialysis, and failed renal transplant) were found to influence participants' perceptions.

Tell et al. (1995) investigated perceived and actual social supports of African-American and Caucasian individuals receiving hemodialysis ($N = 256$). The ISEL assessed perceived social support and the LSNS assessed actual social support. The findings indicated that although most participants reported high levels of perceived support, actual supports were in the moderate to strong range. Gender or race were not found to influence perceived or actual support, even after controlling for age, time on dialysis, and mode of treatment.

In a series of cross-sectional studies, the MSPSS was used to examine perceived social support in the hemodialysis population (Kimmel et al., 1996; Kovac et al., 2002; Patel et al., 2002). The mean MSPSS scores across all studies consistently indicated that participants gave high ratings to their overall support. No significant difference in perceived support was observed between incident and prevalent populations (Kimmel et al., 1996). While Kovac et al.

failed to find any effect for gender, Patel et al. reported that males had significantly lower levels of perceived overall support than females. Age was not found to influence perceived support (Kovac et al.; Patel et al.).

Kimmel et al.(1996) used the DAS to assess participants' satisfaction with dyadic relationships. One dichotomous item assessed dyadic status (i.e., presence of a stable relationship less than or greater than 6 months). Similar to study findings from normative samples, participants were generally satisfied with the dyadic relationship. No significant differences were observed between the incident and prevalent population in terms of the proportion involved in stable dyadic relationships or levels of satisfaction with those relationships. The presence of a stable relationship was associated with greater perceived support in the prevalent, but not the incident population.

Cormier-Daigle and Stewart (1997) examined the support networks and perceived quality of interpersonal relationships of males undergoing hemodialysis. The IPRI assessed the structure (i.e., social network characteristics) and function (i.e., available or enacted support, reciprocity, and conflict) of interpersonal relationships. In order of priority, participants perceived family and relatives, friends, health care providers, and spouses or partners, respectively, as important sources of support. Neighbors, clergy, work or school associates, and peers were infrequent sources of support. While most participants reported high levels of perceived or enacted support and moderate

to high levels of reciprocity, they also reported a moderate level of conflict (i.e., households with larger numbers of people demonstrated greater conflict). Age and marital status did not influence perceived social support.

Kovac et al. (2002) also examined satisfaction with health care providers in individuals on hemodialysis. The revised PSQ was used to measure satisfaction with information received about the illness (i.e., Communication scale) from physicians and other staff (i.e., nursing, dietician, social work, and technical staff) and their affective or caring behaviors (i.e., Affect scale). The mean overall and sub-scale scores for the PSQ indicated participants were relatively satisfied with the care and information provided by physicians and other staff. Age, type of health care provider, and gender were not found to influence satisfaction levels.

A few qualitative studies examined social support in the dialysis population. Similar to findings previously reported, the qualitative data provide insight into the primary sources and usefulness of support. A summary of select studies is provided below.

Kutner (1987) examined support networks of individuals with ESRD on some form of RRT. Participants identified the family as their most important source of informal support. Although family members were seen as being very supportive (i.e., provided encouragement and reinforced the treatment regimes), they were sources of strain (e.g., independence/dependence conflict, burden,

undercaring versus overcaring, etc.). Formal support networks (i.e., dialysis peers and health care providers) were also viewed as important sources of emotional, tangible, and informational support. Dialysis peers provided participants with socializing opportunities and informational support. While participants appreciated the caring behaviors of nurses, they were also subject to variable mood states and technical competence. Because physicians were not always available or accessible, they were considered to be less useful sources of informational and emotional support.

Gurklis and Menke (1995) investigated individuals' perceptions of social supports. The majority of participants identified spouses or significant others as the most frequent sources of support. Other informal sources of support included extended family members, friends, neighbors, God, and church members. Formal sources of support included dialysis nurses and technicians, home health service providers, social workers, and dieticians. While most participants (89%) gave positive ratings to the support provided by relatives and friends, only 38% did so for the supportiveness of the dialysis staff. Finally, slightly less than one-third of study participants felt that they were still alive due to the support received from friends, health care providers, and home health care services, especially during a serious illness event.

Gregory et al. (1998) reported on how individuals receiving hemodialysis perceived informal and formal social support networks. Generally, participants

gave high ratings to the emotional and tangible support received from family and friends (e.g., assisting with health monitoring, information gathering, decision-making, transportation, etc.). Participants also recognized the need to protect others (i.e., spouse, family, and friends) from lifestyle restrictions and the burden of care. Dialysis nurses were more likely to be recognized for providing humanistic care (i.e., caring, valuing, and accepting them as persons) than physicians or other health care providers (i.e., dieticians and social workers). Finally, while dialysis peers provided emotional and informational support, the suffering and/or death of fellow patients was the downside of developing close relationships. In addition, participants appreciated the family like atmosphere on the dialysis unit, and were generally satisfied with the overall quality of care, especially the technical and interpersonal competencies of nurses and physicians.

White and Grenyer (1999) reported on the perceived supportiveness of family members. The findings indicated that most participants were very satisfied with partner relationships (e.g., loving, caring, kind, etc.). Participants were also cognizant of the extra demands and lifestyle restrictions placed on their partners as a result of the illness and treatment.

Weil (2000) explored the sources of hope in individuals receiving hemodialysis ($N = 14$). While the family was identified as the most frequent source of hope, additional sources included friends, spirituality, technology,

control (i.e., freedom to decide to quit dialysis, informed about the illness and treatment, and participation in decision making) and dialysis staff.

Interaction of supports and illness and treatment experiences. Study findings suggest that perceptions of social supports and satisfaction with marital/partner relationships correlate with perceptions of illness and treatment experiences. Although there is some empirical evidence linking perceptions of social supports and illness intrusiveness, the evidence is less convincing on the interrelationships among supports, stressors, self-care practices, knowledge confidence, and medical risk factors. There were no longitudinal data on interrelationships of illness and treatment experiences and support. The following discussion presents a brief overview of relevant findings from select cross-sectional studies.

Kimmel et al. (1996) examined the association of the presence of a stable dyadic relationship, satisfaction with the dyadic relationships, and perceived social support with factors defining the illness and treatment experience and medical risk factors (i.e., biochemical parameters). Greater perceived social support and greater satisfaction with the marital/partner relationship were significantly correlated with lower levels of illness intrusiveness in both the incident and prevalent groups. The presence of a stable dyadic relationship did not correlate with illness intrusiveness in either group. Illness severity was not found to significantly correlate with any of the support measures. Although

medical risk factors (i.e., phosphorus and potassium) failed to significantly correlate with overall support or the presence of a stable relationship in either group, lower phosphorus levels significantly correlated with greater satisfaction with marital/partner relationships in the incident, but not the prevalent, group.

Kimmel et al. (1998) examined the relationship of overall social support with illness and treatment experiences and medical risk factors (i.e., dialysis adequacy, albumin, and illness severity). Greater illness intrusiveness was significantly related to lower levels of perceived support. Medical risk factors failed to correlate with social support.

Kimmel et al. (2000) explored gender differences in how satisfaction with marital/partner relationships and perceived social support correlated with illness intrusiveness and medical risk factors (i.e., dialysis adequacy, illness severity, and albumin). For the most part, significant correlations were only observed in the female portion of the sample. Specifically, greater overall satisfaction with dyadic relationships and lower perceived dyadic conflict were significantly associated with lower perceived illness intrusiveness for the women but not the men. As well, greater dialysis adequacy levels were significantly associated with less dyadic conflict for female but not male participants. Finally, illness severity and albumin were not associated with marital/partner satisfaction or levels of perceived dyadic conflict in either males or females.

Kovac et al. (2002) also examined the relationship of satisfaction with staff

and physician caring behaviors (i.e., Affect scale) and illness-related information sharing (i.e., Communication scale) with select medical risk factors (i.e., illness severity, potassium, albumin, phosphorus, dialysis adequacy, and protein catabolic rate). While greater satisfaction with informational and caring behaviors of physicians and staff correlated significantly with greater albumin levels, only greater satisfaction with physician caring and informational behaviors significantly correlated with greater protein catabolic levels. Finally, no significant associations were found between patient satisfaction levels and the remaining medical risk factors.

Patel et al. (2002) investigated the relationship between perceived illness intrusiveness and patient satisfaction with physicians and staff (i.e., perceived encouragement and support, satisfaction with care, and respect). While greater satisfaction with physicians was significantly correlated with lower perceived illness intrusiveness, satisfaction with dialysis staff failed to correlate with perceived illness effects.

Summary. The empirical evidence suggests that social support is an important factor to consider when exploring the impact of ESRD and its subsequent treatment. Specifically, individuals perceived informal networks to be most supportive, with family given the highest ratings. While the ratings of formal support networks varied across studies, health care professionals were seen as important sources of emotional, informational, and tangible support.

A paucity of research studies were identified that examined how perceptions of social support and satisfaction with dyadic relationships correlated with perceived illness intrusiveness, medical risk factors, and demographic variables. However, study findings were fairly consistent on the significant association of greater overall social support and greater satisfaction with dyadic relationships with lower perceived illness intrusiveness. No studies were reviewed that examined the link between social support variables and self-care practices and knowledge confidence. Demographic variables and medical risk factors were found to exert minimal influence on perceptions of social supports and satisfaction with dyadic relationships.

Adjustment to a New Normal

A review of the literature dealing with adjustment revealed that individuals with ESRD are continuously having to redefine themselves in response to the illness and treatment. Losses from chronic illness have been variantly described as a weakening of the self or as an opportunity for redefining the self (Charmaz, 1987; Kleinman, 1988; Morse & Johnson, 1991). Adaptation to this new self depends on how individuals react to, perceive, and cope with the illness and treatment and how these reactions and perceptions are influenced by the quality and availability of social support networks. The ability to maintain previous roles and identity within the context of the dialysis world (i.e., restrictions associated

with the illness and treatment regimes) is a struggle for these individuals.

This section provides a review of the literature related to how individuals adjust to chronic ESRD and dialysis. Consideration will be given to coping strategies employed by these individuals to facilitate adjustment. Adjustment will be examined from the perspective of emotional well-being and psychosocial distress. Finally, examination of factors influencing emotional well-being and psychosocial distress will be reviewed.

Constructing a new self. Adjustment to ESRD and its subsequent treatment require that individuals depend greatly on others while at the same time attempt to come to terms with what is happening to them. The desire for independence conflicts with the dependency on others for survival, thus causing turmoil within the individual. The integration of a rigorous illness and treatment regime force these individuals to reconstruct themselves within the context of living with a chronic illness and the restrictions imposed on them. This section is restricted to several qualitative studies that documented how these individuals rise above the old self and construct a new identity as they adapt to the effects of ESRD and hemodialysis.

In a longitudinal study, O'Brien (1983) investigated emotional reactions to illness and treatment regimes in individuals with ESRD ($N = 126$). The study findings suggested that perceptions of the self fall along a continuum of three modes (i.e., sickness, chronic illness, and wellness) that are differentiated by

different attitudes and behaviors. While the sickness mode is characterized by dependency, anxiety, and withdrawal, the chronic illness mode is characterized by acceptance, trust, and social interaction with family and friends. Finally, the wellness mode is dominated by independence, control, and involvement in work/career. The researchers noted that individuals did not stay in one mode but traversed back and forth along the continuum in terms of changes in health states (i.e., positive or negative physical and psychological events). They also noted that some individuals never move beyond the sickness mode. Participants also indicated how difficult it was to maintain a wellness perspective when they were constantly faced with social isolation and uncertainty about the future.

Kutner (1987) investigated how individuals' experiences with illness can help shape emerging personal identities. The study findings suggested that choice of treatment modality is contingent upon individual preferences and needs. While individuals who choose home dialysis or transplant may be separating themselves from the dialysis facilities with the desire to appear like normal, well individuals, their counterparts choosing in-center hemodialysis may need support from dialysis peers and staff. As well, in-center dialysis may generate a sense of productivity (i.e., viewed as work). Although some satisfaction may be derived from being able to choose among treatment options, these individuals still live an artificial existence. Study participants struggled with the disparities experienced between the physical persona and the internal self

(i.e., not well but not ill) resulting in oscillating positioning on the sickness-wellness continuum. This struggle was compounded by the desire to be normal while being faced with an illness that is considered to be permanent and totally disabling. Finally, participants reported being torn between a desire for productivity and independence while not jeopardizing financial security (i.e., disability income and benefits).

Rittman, Northsea, Hausauer, Green, and Swanson (1993) used an hermeneutics, phenomenological design to examine how individuals' experienced living with chronic renal failure and dialysis ($N = 6$). Three major themes (i.e., taking on a new understanding of being, maintaining hope, and dwelling in dialysis) were identified during data analysis. A new sense of being emerged after individuals integrated and accepted the illness and treatment as part of their normal life. Maintaining hope was seen as an important coping strategy for envisioning new possibilities for the future (i.e., successful kidney transplant, watching their grandchildren grow up). Dwelling in dialysis reflected acceptance of the dialysis world as a second home. As the dialysis world became the new context for being, the dehumanizing effects of technology were counteracted and control was maintained by being territorial (i.e., wanting same space and machine every treatment). Control: the meaning of technology was the unifying thread connecting the three major themes. The restrictions imposed by the medical regime required individuals to develop a new relationship with the

self and relinquish control of bodily functions to technology. As individuals struggled with technological dependency, they tried to regain some element of control by testing the boundaries of the restrictions (i.e., food and fluid).

Gregory et al. (1998) reported on changes in the self over time. The construct of redefining the self was seen as an interactive process dependent on current health states, technology, stressors, treatment routines, major lifestyle restrictions, interference in roles and responsibilities at home and work, and the remembered old self. The daily struggle of having to live with and adapt to restrictions imposed by the treatment regime transformed the old self into a new self. Individuals ability to maintain a positive attitude was compromised by an unpredictable illness course (i.e., feeling physically well and then experiencing a downward swing). While dependence on technology impaired one's sense of confidence in the physical self, positive changes in health and well-being facilitated acceptance of the illness and treatment requirements. As well, negative changes in health became a barrier to adjustment. The emotional upheaval and uncertainty about the future often resulted in feelings of hopeless, dependence, humiliation, and inadequacy as individuals struggled to be positive about the illness and treatment.

Nagle (1998) explored the meaning of technology for individuals receiving hemodialysis. Coming to terms with losses and limitations, abiding with technology, and enduring the treatment environment emerged as the dominant

themes. Coming to terms captured how individuals struggled with the reality of multiple losses and limitations and dependence on technology, while trying to retain a sense of normalcy. Abiding with technology was described as integrating technological dependence in a meaningful way into one's lived world. While reliance on technology and others for survival necessitated redefining the self, a sense of normalcy (i.e., autonomy and control) was maintained by becoming informed and becoming active participants in monitoring the physical self and the care provided by others. Finally, enduring the treatment environment captured participants desire to be recognized not only as individuals but also as integral members of the dialysis community, to be informed and involved in decision-making, and to have access to a supportive dialysis environment (i.e., conducive physical, social, and cultural environment).

Faber (2000) investigated the life experiences of individuals on hemodialysis. Adjustment to living with a chronic illness was captured in three major themes (i.e., the work of living with ESRD, living with the losses of ESRD, and the work of others). The work of living with ESRD was defined in terms of becoming informed decision makers (i.e., knowledgeable about the illness and treatment options), struggling to accept and normalize events of the dialysis world (e.g., seeing others become ill, exposure to the variant moods and competency of others, time commitment, etc.), and trying to incorporate a rigorous medical regime (e.g., food and fluid restrictions, scheduling of treatment

times, etc.) into normal life. The living with losses theme captured how individuals struggled with physical, cognitive, and psychosocial limitations in order to maintain some semblance of a normal life. The final theme, the work of others, addressed how family members not only had to endure losses (i.e., restrictions imposed by the illness and treatment in many life domains) but also assume a supportive role.

Coping with ESRD and hemodialysis. The challenge of successfully adjusting to a new normal requires that individuals employ appropriate coping strategies to help deal with the stress of the illness and treatment and social supports. Studies were identified from the literature review that examined the type of coping strategies (i.e., problem-oriented or affective-oriented) used by individuals with ESRD and receiving dialysis. Although no longitudinal studies were found, there were a few quantitative and qualitative studies.

A number of previously mentioned studies examined coping strategies used by individuals receiving hemodialysis to manage illness- and treatment-related stressors (Baldree et al., 1982; Gurklis & Menke, 1988; Lok, 1996). The original Jalowiec Coping Scale (JCS) was used to assess the type and frequency of coping strategies. The JCS was reported to have content validity and high test-retest reliability by all authors. Study findings indicated that participants used coping strategies rarely to sometimes to manage illness- and treatment-related stressors (Baldree et al.; Gurklis & Menke). Most participants tended to

rely on problem-oriented strategies more than affective-oriented ones, with looking at the problem objectively, accepting the situation as it is, trying to maintain control, and being hopeful surfacing as the dominant strategies (Baldree et al.; Gurklis & Menke; Lok). The empirical association between coping strategies and stressors or demographics varied considerably across the studies. While Baldree et al. failed to find any association between stressors and coping strategies, Gurklis and Menke found that greater use of both problem and affective coping significantly correlated with increased overall and psychological stressors. Although Lok found that greater use of problem-oriented strategies was significantly related to increased overall stressors, less use of these strategies significantly associated with increased physiological stressors. While Gurklis and Menke found that greater time on dialysis was significantly related to greater use of problem-oriented strategies, Lok and Baldree et al. failed to find such an effect. Finally, Baldree et al. failed to document a significant link between coping strategies and demographic factors (i.e., age, gender, and marital status). Inconsistent findings may be related to small sample sizes.

Klang, Bjorvell, and Cronqvist (1996) used the revised JCS to investigate the type of coping strategies used by individuals undergoing hemodialysis for three to nine months ($n = 23$). The JCS depicted three major types of strategies (i.e., confrontational, emotive, and palliative). The findings indicated that these individuals rarely used coping strategies to deal with illness and treatment

stressors. The most frequently used strategies were confrontational (i.e., trying to maintain control, looking at the problem objectively, actively trying to change the situation, and setting specific goals), palliative (i.e., going to sleep, things will be better in the morning), and emotive (i.e., get nervous and worry), respectively. The small sample was a limitation of the study.

Blake and Courts (1996) examined gender differences in coping strategies in a sample of individuals receiving hemodialysis ($N = 30$). The revised JCS assessed coping in eight content domains (i.e., confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant). The mean scores indicated that both males and females rarely used coping strategies. Although no significant difference was observed in overall coping, gender variations were noted in the use of specific strategies. The strategies used most frequently by men included keeping life normal, thinking good thoughts, controlling feelings, keeping busy, and thinking positively, respectively. In contrast, strategies used by females included taking things one step at a time, telling the self it is possible to handle anything, praying to and trusting God, distracting oneself, and viewing problems objectively, respectively. Although there was a greater tendency to use affective-oriented strategies more often than problem-oriented ones overall, women had a tendency to used problem-oriented strategies slightly more than men. Finally, increased age was related to the increase use of affective-oriented strategies. The small sample was a limitation of the study.

Cormer-Daigle and Stewart (1997) assessed coping in males undergoing hemodialysis. The Ways of Coping (WOC) questionnaire assessed coping in terms of problem-focused (i.e., seeking social support, problem-solving, positive reappraisal, and confrontive coping), affective coping (i.e., distancing, escape-avoidance, and accepting responsibility), and self-controlling. The WOC subscales were reported to have acceptable internal consistencies. Participants relied on problem-oriented strategies significantly more often than affective oriented strategies. The most frequently identified coping strategies included seeking social support, self-controlling, distancing, and positive reappraisal, respectively. The only significant correlation observed between stressors and coping strategies was a greater tendency to use escape-avoidance in dealing with illness-related, as opposed to, treatment-related stressors. Limited significant correlations were observed between coping strategies and supports. Specifically, while increased use of positive re-appraisal strategies correlated with greater reciprocity and a lesser number of close relatives, increased use of avoidance/escape strategies correlated with a greater number of household members. Age and marital status did not significantly correlate with type of coping strategy.

Qualitative studies were also reviewed that explored how individuals with ESRD receiving hemodialysis coped with illness- and treatment-related stressors. The findings of three studies are summarized below.

Kutner (1987) reported on how individuals cope with the uncertainty associated with ESRD and hemodialysis. Participants comments indicated that the uncertainty about the future played havoc with their ability to completely adjust to and accept the illness and treatment. Many participants coped with the uncertainties by focusing on the positives (i.e., making an extra effort to enjoy sunsets and laughter of kids). Finally, participants ability to cope was enhanced through their spiritual beliefs and support received from their existing social (i.e., family and friends) and emerging social worlds (i.e., dialysis staff and peers).

Gurklis and Menke (1995) examined coping in individuals with ESRD receiving hemodialysis. Forty-eight coping strategies were identified and collapsed into six major categories: accepting being on hemodialysis (i.e., perceiving dialysis as a lifeline), maintaining control (i.e., active participation in care), maintaining a positive attitude (i.e., normalizing illness and dialysis), remaining active (i.e., social, recreational), self-mastery (i.e., independence, self improvement activities and controlling one's emotional responses), and support (i.e., family, friends, and professional). All of these strategies were interrelated and used by participants to manage stress. The researchers noted that these findings validated the findings in quantitative studies.

In the study by Weil (1999), the meaning of hope was explored in individuals on hemodialysis. Hope was defined in terms of a positive future outlook (i.e., hope for medical breakthroughs to shorten hemodialysis), striving to

accept illness and treatment restrictions, maintaining an optimal level of well-being, and having a sense of spirituality. Participants indicated that technology, maintaining a healthy state, maintaining control (i.e., involved in decision making), spirituality, support from family and friends, and participation in recreational activities (i.e., family activities, exercising, dining out) facilitated coping with the illness and treatment.

Well-being and distress. An examination of the literature revealed information related to well-being and distress in the ESRD population, however, confusion arises when one attempts to differentiate between the two. The conceptual overlap of the terms make cross study comparisons challenging. Many researchers use the constructs of emotional well-being and psychological distress to assess adjustment to illness and treatment and/or QOL. In a meta-analysis by Cameron, Whiteside, Katz, and Devins (2000), two psychosocial constructs are described that represent indicators of QOL in ESRD (i.e., emotional distress and psychological well-being). Although confusion exists over the language used, the two constructs seen depict a continuum of health (i.e., well and ill).

Distress has been investigated using various indicators (i.e., depression, anxiety, mood states, and psychosocial maladjustment). Numerous operational measures have been used to assess distress in the hemodialysis population (i.e., Profile of Mood States [POMS], Psychosocial Adjustment to Illness Scale [PAIS],

Beck Depression Inventory [BDI] and its subset the Cognitive Depression Index [CDI], Social Adjustment Scale - Self Report [SAS-SR], the Center for Epidemiologic Studies Depression Scale [CESDS); Strait-Trait Anxiety Scale [STAI], Brief Symptom Inventory [BSI], and Hospital Anxiety and Depression Scale [HADS]). Similarly, various indicators (i.e., life satisfaction, happiness, and positive affect) and instruments (i.e., Acceptance of Illness Scale [AIS], Bradburn Affect Balance Scale [BABS], Life Happiness Rating [LHR] scale, Self-Esteem Inventory [SEI], and Affect Scale [AS]) have been used to explore the well-being construct. While a few studies were identified from the literature review that examined changes in well-being and distress levels over short time periods, most of the studies were cross-sectional. Several researchers also examined the influence of diverse factors (i.e., stressors, illness intrusiveness, social supports, demographics, and medical risk factors) on well-being and distress. The following discussion highlights study findings on the well-being and distress levels of hemodialysis patients, and how these levels may change in response to select influencing factors.

Parfrey et al. (1989) reported on changes in the frequency and severity of emotional symptoms in a sample of stable dialysis patients. The AS assessed emotions (i.e, determination to carry on, why me, different from others, faith that things will be okay, angry, scared, helpless, alone, fed up, sad, desperate, and other). Good reliability and validity was reported for the scale. Study findings

revealed that most participants experienced mild emotional symptoms over a one year period.

Klang and Clyne (1997) investigated anxiety in the dialysis population. The STAI measured anxiety. Reliability and validity for the STAI was reported to be high. Study findings at both pre-dialysis and 3 to 9 months following dialysis initiation revealed that most participants had mild anxiety. Age, mode of treatment, gender, and serum creatinine levels did not significantly correlate with anxiety. Although the sample size was small, the longitudinal design increases the credibility of the results.

Lev and Owen (1998) used the POMS as a measure of adjustment to illness and treatment in the hemodialysis population. Consideration was also given to the relationship of self-care self-efficacy (i.e., coping, stress reduction, making decisions, and enjoying life) to adjustment. The POMS assessed affect and feelings along six dimensions (i.e., tension-anxiety, depression-dejection, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment). Participants reported mild mood distress at all time periods (i.e., average of 100 days post initiation of hemodialysis, 4-months, and 8-months). The most problematic area at all time periods was vigor, followed by fatigue and tension, respectively. There was evidence of inconsistent relationships between self-care self-efficacy and mood distress over time. At baseline, only increased use of stress reduction strategies and decision making significantly correlated with

increased vigor. At 4-months increased confidence in coping was significantly related to decreased tension, depression, anger, fatigue, and increased vigor. As well, employing more strategies to enjoy life significantly correlated with increased vigor and decreased fatigue. At 8-months increased use of all four strategies was significantly related to increased vigor.

Kimmel et al. (1998) also examined the interrelationships among overall depression, cognitive depression, negative illness effects, illness severity, and select biochemical parameters (i.e., albumin and dialysis adequacy). The BDI and CDI assessed overall and cognitive depression, respectively. The findings revealed that participants had mild depression over time (i.e., study initiation, 6-months, and 12-months). Greater overall and cognitive depression significantly correlated with greater perceived illness intrusiveness. However, depression levels failed to significantly correlate with illness severity, biochemical parameters, or age.

A number of cross-sectional studies were also identified that examined well-being and distress levels in the hemodialysis population. Overall, study findings suggested that participants report experiencing low levels of distress and good overall well-being. Select studies are summarized below.

Barrett et al. (1990) examined the effects of physiological stressors on the well-being of individuals receiving dialysis ($N = 96$). The AS was used for data collection. The findings indicated that increased severity of physiological

stressors was significantly correlated with poorer affect.

Seigal et al. (1987) investigated the effects of social supports, demographic factors (i.e., age, gender, race, marital status, education, and work status), and time on hemodialysis on the psychological adjustment of individuals receiving hemodialysis. The BSI was used to assess the presence and frequency of psychological symptoms. Study findings indicated that participants reported more psychological symptoms (i.e., depression, anxiety, and somatic complaints) than the normal population. While the quality and quantity of support from health care providers failed to significantly correlate with psychological adjustment, greater perceived quality, but not the quantity, of support from family and friends significantly correlated with better psychological adjustment. Finally, active employment and on dialysis for longer periods of time significantly correlated with better psychological adjustment.

Sacks et al. (1990) investigated the interrelationships among role disruptions, overall and cognitive depression, perceived illness intrusiveness, blood urea nitrogen, creatinine, and illness severity in a sample of individuals receiving hemodialysis (n = 43) and peritoneal dialysis (n = 14). A modified version of the SAS - SR was used to assess disruptions in employment, social and leisure activities, and marital, family and parental role functioning. The SAS - SR was reported to have good reliability and validity. The BDI and CDI assessed depression levels. Study findings indicated that most participants

experienced minor role disruptions and mild levels of overall and cognitive depression. As well, 26% of the sample reported moderate depression. No significant differences were observed between the hemodialysis and the CAPD groups for either depression or role disruptions. Greater overall and cognitive depression significantly correlated with greater illness intrusiveness. While greater overall depression was significantly correlated with greater illness severity, cognitive depression failed to achieve significance. Greater perceived illness intrusiveness, overall depression, and illness severity were significantly associated with greater role disruptions. Older participants were significantly more likely to have higher levels of overall depression and greater role disruptions. While females had significantly higher levels of cognitive depression than males, there were no gender differences for overall depression or role disruptions. Length of time on dialysis, blood urea nitrogen, and creatinine failed to correlate with either depression levels or role disruption.

Kimmel et al. (1995) examined the influence of illness intrusiveness, illness severity, depression, physical functioning, overall social support, presence of a committed relationship, satisfaction with dyadic relationships, and select biochemical parameters (i.e., phosphorus and potassium) on psychosocial adjustment levels in a prevalent hemodialysis population. Three subscales of the PAIS (i.e., vocational, relationship-sexual, and social environment) were used to assess psychosocial adjustment. The BDI and CDI assessed depression levels.

Study findings indicated that participants were adjusting well in all three domains and had low levels of overall and cognitive depression. More positive perceptions of illness effects and greater perceived social support were significantly related to improved vocational adjustment to the illness. As well, more positive perceptions of illness effects, lower levels of cognitive depression, less illness severity, younger age, the presence of a stable dyadic relationship, and greater satisfaction with dyadic relationships were significantly related to improved family and sexual relationships. More positive perception of illness effects, lower levels of cognitive depression, greater perceived social support, lower illness severity, and younger age were significantly related to greater social adjustment to the illness. Greater perceived social support, greater satisfaction with dyadic relationships, and less perceived illness effects were significantly related to lower levels of cognitive depression. Although lower potassium levels demonstrated a significant relationship to greater social adjustment, phosphorus was not found to influence any of the three adjustment domains. Finally, while increased phosphorus levels demonstrated a significant relationship with greater overall depression, illness severity and potassium failed to associate with overall depression levels.

Kimmel et al. (1996) reported on factors that influenced adjustment in an incident hemodialysis population. Study instruments were the same as those used by Kimmel et al. (1995). The mean scores suggested participants were

adjusting well in all three domains and had low levels of overall and cognitive depression. The only significant difference observed between the incident and prevalent population was in the family and sexual relationship domain, with the incident group reporting better adjustment. More positive perceptions of illness effects and lower levels of overall and cognitive depression were significantly correlated with greater vocational adjustment. As well, more positive perceptions of illness effects, lower levels of overall and cognitive depression, greater perceived social support, and greater satisfaction with dyadic relationships were significantly correlated with greater social adjustment to illness. More positive perceptions of illness effects, lower levels of overall and cognitive depression, and greater satisfaction with dyadic relationships were significantly correlated with greater adjustment to family and sexual relationships. Greater perceived social support, greater satisfaction with dyadic relationships and less perceived illness effects were significantly related to lower levels of overall and cognitive depression. Illness severity, potassium, and phosphorus failed to correlate with overall or cognitive depression or any of the adjustment domains.

Killingworth and Van Den Akker (1996) examined adjustment to illness in individuals undergoing hemodialysis. The PAIS assessed adjustment to illness and the HADS assessed anxiety and depression levels. The findings indicated that the majority of participants had mild to moderate adjustment difficulties. Participants indicated greatest difficulty with vocational and sexual adjustment. A

significant number of the participants evidenced borderline anxiety and depression (48% and 55%, respectively). Increased frequency of physical symptoms was significantly correlated with greater anxiety, greater depression, and greater maladjustment. Finally, greater anxiety and depression levels were significantly correlated with greater maladjustment. Age, gender, and time on hemodialysis failed to exert any influence on anxiety or depression.

Devins, Beanlands, Mandin, and Paul (1997) examined the relationship between well-being, distress, illness intrusiveness, and self-concept in a sample of individuals on some form of RRT ($N = 101$). Well-being was assessed using three instruments (i.e., BABS, LHR, and SEI). Emotional distress was assessed using the CES-D and the POMS. Self-concept was assessed using the semantic differential technique where individuals rated two concepts (i.e., myself as I am now and chronic kidney patient). In addition, a checklist of recent stressful life events was completed. All instruments were reported to have strong psychometric properties. Increased frequency of stressful life events and uremic symptoms were significantly correlated with increased emotional distress. Fewer comorbid illnesses and uremic symptoms, longer illness duration, and paid employment were significantly related to increased psychosocial well-being. When uremic symptoms and stressful life events were controlled for during multiple regression analysis, greater age and less illness intrusiveness were predictive of less distress and greater psychosocial well-being. As well,

increased levels of illness intrusiveness resulted in increased emotional distress when individuals perceived themselves as similar to the chronic kidney patient. With younger individuals, increased levels of illness intrusiveness resulted in decreased psychosocial well-being when individuals perceived themselves as dissimilar to the chronic kidney patient. The opposite effect was evident in older individuals (i.e., greater illness intrusiveness with decreased psychosocial well-being when the self was perceived as similar to the chronic kidney patient).

Keogh and Feehally (1999) examined acceptance and adjustment in individuals on RRT ($N = 273$). The AIS was used to assess illness acceptance. The instrument was reported to have high internal consistency and reasonable test-retest reliability. Most participants had moderate levels of acceptance of illness and treatment. While the transplant group had higher levels of illness acceptance than the dialysis groups, no difference was observed between the dialysis groups. Younger age and currently employed demonstrated a significant, but low, correlation with higher levels of illness acceptance. Gender, marital status, and time on RRT failed to achieve significance.

Kimmel et al. (2000) investigated gender differences in overall and cognitive depression levels of hemodialysis patients. The BDI and CDI were used for data collection. The findings indicated that most of the men and women had mild overall and cognitive depression. Greater satisfaction with the dyadic relationship and lower perceived dyadic conflict were significantly associated with

lower levels of overall and cognitive depression in both males and females. High levels of depression were significantly correlated with greater illness severity in women but not men.

Kovac et al. (2002) and Patel et al. (2002) also used the BDI and CDI to assess overall and cognitive depression in the hemodialysis population. The findings from both studies indicated that participants had low levels of overall and cognitive depression. While Patel et al. found that males had significantly higher levels of depression than females, Kovac et al. failed to document such an effect. Patel et al. also failed to document a significant effect for age.

Walters et al. (2002) examined the association of depression with select demographics (i.e., age, gender, and race) and medical risk factors (i.e., illness severity, hemoglobin, hematocrit, and creatinine) in individuals within the first sixty days of initiation of hemodialysis. Three items from the Diagnostic Interview Schedule assessed depression. The findings indicated that 45% of the participants scored positive on the depressive screening measure. None of the demographic or medical risk factors were found to influence depression levels.

Summary. Qualitative study findings highlighted how individuals create a new sense of self when faced with ESRD and long term dialysis regimes. While constant shifts in normalcy pose difficulties in the physical, emotional, psychological, social, and spiritual spheres, qualitative and quantitative study findings suggested that most people are coping well. Although most quantitative

study findings provided evidence of fairly high levels of well-being (i.e., mild dysfunction in health-related domains) and low levels of distress (i.e., low levels of overall and cognitive depression, anxiety, mood disturbance, and psychosocial maladjustment), a significant number of individuals experienced maladjustment difficulties and suffered from clinical depression.

While there is limited, and sometimes contradictory, information on factors influencing adjustment to a new normal, there is some indication that illness and treatment experiences and social supports play a significant role. The evidence is fairly consistent on both the positive effects of social supports and the negative effects of physiological stressors and perceived illness intrusiveness on distress levels (i.e., anxiety, depression, and psychosocial adjustment) and emotional well-being. In contrast, demographic and medical risk factors seem to play a minor role in determining adjustment levels. While factors influencing well-being and distress have been given some attention, lack of prospective data to support whether these factors change over time make it impossible to draw conclusions, thus making interventions difficult to implement.

Summary

The review of the literature provides insight into factors that influence adjustment to ESRD and hemodialysis. The uncertainties surrounding the illness and treatment are complex and are further complicated by physical and

psychosocial stressors, perceptions of illness intrusiveness, availability and helpfulness of social support networks, and adjustment difficulties. Individuals are constantly having to redefine themselves within the context of many separate and interacting effects. The majority of the studies reviewed used cross-sectional designs, small, convenience samples, and diverse operational indicators for major variables. Nevertheless, study findings on various aspects of illness and treatment experiences, social supports, and adjustment were, for the most part, fairly consistent. Longitudinal data are required to determine conclusively the specific areas that facilitate and influence adjustment. Only then can appropriate interventions be directed at ways to improve adjustment.

Quality Outcomes: Individuals with ESRD Undergoing Hemodialysis

Quality outcomes can be referred to as the end result of particular interventions. The goal of ESRD and hemodialysis is not only to maintain life, but to achieve the highest possible level of functioning and well-being. One of the challenges encountered in the literature review was grasping an understanding of the similarities and differences among the operational measures used to assess outcome. QOL is one of the most frequently assessed outcomes with the ESRD population. The following discussion is limited to studies focusing on the QOL construct.

QOL Construct

An extensive array of theoretical perspectives and research findings on QOL in the ESRD and dialysis population was identified. Many researchers used the global term QOL to represent overall well-being and satisfaction with important life domains. Other researchers preferred to use the term HRQOL to reflect how current health impacts functioning and well-being in various life domains. Controversy was evident concerning the best approach to use to measure outcome (i.e., generic versus disease-specific instruments). Generic instruments have been used in a wide variety of populations and allow one to compare different groups (Edgell et al., 1996; Kutner, 1994; Valderrabano, Jofre, & Lopez-Gomez, 2001). Disease specific instruments focus on specific diseases and problems associated with them, specific groups, and areas of function, and are believed to be more sensitive to changes in disease- or treatment-related factors (Valderrabano et al., 2001). The following discussion presents a brief overview of the perspectives taken by different authors.

Kutner (1994) provided an overview of conceptual and operational measures used to assess functioning and well-being as outcomes in ESRD. The author uses the definitions of functioning and well-being as put forward by the Medical Outcomes Study Framework of health indicators. Functioning is defined as the ability to perform various activities and functions of daily living. Well-being is defined as subjective internal states that are not observable by others (i.e.,

feelings). Kutner suggested that functioning and well-being are assessed with instruments that measure functional outcome, health status, and HRQOL. Using the definition from Patrick (1990), Kutner defines HRQOL as physical, psychological, and social functioning and activities as well as satisfaction with health. Kutner used the concepts of functioning and well-being to reflect how individuals are doing and how they perceive their health and its effects on their life. The author suggested that assessments of functioning and well-being emphasize types of outcomes that reflect the influence of chronic illnesses (e.g., ESRD, etc.). The importance of obtaining the patient's perceptions of functioning and well-being is emphasized. It is recommended that both generic and disease specific instruments be used for comparison purposes.

Gill and Feinstein (1994) carried out an apprisal of QOL instruments to determine how this construct is measured in the medical literature. The review consisted of 75 articles. The authors noted that many researchers substituted QOL for other terms (i.e., health status or functional status). The findings indicated that QOL was defined in only 15%, targeted domains were identified in 47%, rationale for chosen instrument in 38%, and aggregate scores for QOL in 38% of the articles. As well, no researchers differentiated between QOL and HRQOL. Participants were asked to provide a separate rating for QOL in 17% and supplementary information in 13% of the articles. Individuals were asked to rate the importance of scale items in only 8.5% of the articles. It was concluded

that most measurements of QOL appear to be misdirected. The authors recommended the use of global ratings of QOL and HRQOL to distinguish between the two concepts, patients' ratings of structured items, and open-ended questions to allow patients to comment on important factors not included in instruments.

Edgell et al. (1996) completed a review of operational measures of HRQOL used in ESRD. The authors describe instruments that assess physical, mental, and social aspects of health as well as generic and disease specific instruments that assess functioning and well-being in various life domains. The authors concluded that many of the instruments have not demonstrated reliability and validity in the ESRD population. It is suggested that generic instruments may not be sensitive to specific HRQOL concerns of the individuals with ESRD, and that disease specific instruments are more likely to be relevant and sensitive to changes in HRQOL and the impact of treatment on one's life. Edgell et al. recommended that a combination of generic and disease specific instruments may be the best approach with this population.

Haas (1999) used Walker and Avant's (1995) model of concept analysis to examine the QOL construct. Following a review of 32 articles related to QOL, Haas proposed that the construct is multidimensional, poorly defined, value based, has many interpretations, and comprises both subjective and objective indicators. The author concludes that QOL should be defined as a sense of well-

being represented by four major domains of health (i.e., physical, psychological, social, and spiritual) that contribute to overall well-being and functional status.

Cagney et al. (2000), in an extensive review of the literature on QOL instruments used in ESRD, reported that there were 113 uses of 53 different instruments, with 82% generic and 18% disease specific. As well, only 32% defined the QOL construct. Cagney et al. concluded that many of the generic instruments lacked clinimetric testing with this population.

A more recent conceptualization of HRQOL as it relates to ESRD was put forward by Valderrabano et al. (2001). According to these authors, HRQOL, although not well defined, refers to a measure of an individual's functioning, well-being, and general health perception. Three content domains (i.e., physical, psychological, and social) are identified with each domain comprising several dimensions. The physical domain measures functional and work capacity; the psychological domain measures satisfaction, well-being, self-esteem, anxiety, and depression; and finally, the social domain assesses labor rehabilitation, pastimes, and family and social interaction.

While it is clear the two constructs (i.e., QOL and HRQOL) measure different aspects (i.e., satisfaction versus functioning), confusion and conceptual overlap is still evident. The following presentation of findings is limited to studies dealing with different aspects of HRQOL.

Research Findings on HRQOL

Several longitudinal and cross-sectional studies were designed to investigate the physical and mental functioning of hemodialysis patients. These studies evidenced the use of several generic and disease-specific instruments (e.g., Spitzer Quality of Life Index [SQLI], Medical Outcomes Study Short Form 36 [SF - 36], Kidney Disease Quality of Life Index [KDQOL], Swedish HRQOL Survey [SWED-QUAL], Padilla's Quality of Life Index, Campbell's Index of Well-Being [CIWB], the Karnofsky Scale ([KS], etc.). While there were indications of mild to severe functional limitations on most aspects of physical health, this trend was not observed for most aspects of mental health (i.e., minimal limitations). A brief overview is presented of study findings.

Parfrey et al. (1989) investigated the physical and mental functioning of individuals undergoing hemodialysis over a one year period. Subjective functioning was assessed with the SQLI. Objective functioning was measured with the KS and the Spitzer concise QLI. Campbell's Index of Well-Being and the life satisfaction scale were combined to generate an overall well-being score. The findings indicated that participants had mild levels of functional impairment and were moderately satisfied with their overall physical and mental functioning, which for the most part were stable over time. The one exception was the small, but significant, improvement noted in objective functioning in stable dialysis patients across the time periods.

Klang and Clyne (1997) used the SIP to assess functioning in 12 areas (i.e., sleep and rest, eating, home management, work, recreation and pastimes, body care and movement, ambulation, mobility, emotional behavior, social interaction, and communication) over an average of twelve months. Reliability and validity of the SIP was reported to have been established. Study findings at both baseline and follow-up revealed that most participants had minor functional disabilities. No significant changes were noted in overall functioning and most activity areas between pre-dialysis (i.e., average of 7 months) and post-dialysis (i.e., average of 4 months). While interference with work-related activities significantly increased, recreation and pastime problems significantly declined following dialysis initiation. Although the sample size was small ($N = 28$), the longitudinal design increases the credibility of the results.

Lev and Owen (1998) used the SIP as a measure of functioning in the hemodialysis population. Participants reported mild functional disabilities at all time periods (i.e., average of 100 days post initiation of hemodialysis, 4-months, and 8-months). The most dominant dysfunctional areas at all time periods were interferences with home management, sleep/rest, recreation, ambulation, and social. There was evidence of a slight improvement in functioning in most areas between baseline and four months, with the exception of recreation. The findings between four months and eight months post treatment were inconsistent across the areas (i.e., increases, decreases, or no change).

The majority of studies reviewed that dealt with HRQOL in the ESRD population used cross-sectional designs. A brief summary is presented of study findings.

Meyer et al. (1994) presented cross-sectional data on the physical and mental health of individuals receiving some form of dialysis ($N = 112$), the majority (74%) of whom were on hemodialysis. The SF - 36 assessed health-related functioning and well-being in eight life domains (i.e., physical functioning, role functioning physical, bodily pain, perceived health, social functioning, role functioning emotional, vitality, and mental health). Study findings supported a highly reliable SF - 36. While the mean scores were indicative of substantial impairments in role functioning physical, participants also reported moderate limitations in the remaining life domains. The scores were also lower than population norms. The most problematic areas were in role functioning physical, perceived health, vitality, and physical functioning, respectively.

Tell et al. (1995) examined the HRQOL of persons receiving hemodialysis. The KS was used to assess objective and subjective functioning. One dichotomous item (i.e., yes/no) assessed whether the renal disease interfered with leisure time functioning. The findings indicated that most participants had mild functional limitations, and reported experiencing limitations in leisure time activities.

The KS was used in several other cross-sectional studies to assess

objective physical functioning (Kimmel et al., 1995; Kimmel et al., 1996; Patel et al., 2002; Kovac et al., 2002). The findings across all studies indicated that participants had mild functional limitations (i.e., some assistance required). No significant difference was observed in functioning between the incident and prevalent groups (Kimmel et al., 1996).

Killingworth and Van Den Akker (1996) used the End Stage Renal Function Activity of Daily Living (ESRF-ADL) scale to assess functional limitations in mobility, kitchen and domestic tasks, self-care, and leisure activities. The mean overall score indicated that a significant number of participants (43%) were experiencing difficulties performing ADL. Examination of subscale scores revealed that some respondents had difficulty with domestic tasks (46%) and mobility (30%).

Lok (1996) used Padilla's et al. (1993) QLI to examine functioning and well-being in three life domains (i.e., physical conditions, social activities, and general QOL). The instrument demonstrated high reliability. Participants' ratings were below normal levels in all life domains. Significantly, only 28.5% of the hemodialysis participants indicated that they were generally satisfied with their QOL.

DeOreo (1997) used cross-sectional data from a historical, prospective study to examine physical and mental health in the hemodialysis prevalent population (N = 1000). The SF - 36 was used for data collection. Overall

physical health (i.e., composite score of role functioning physical, physical functioning, perceived health, and bodily pain) and mental health (i.e., composite score of role functioning emotional, mental health, vitality, and social functioning) scores were computed. The findings indicated that participants experienced mild to severe functional limitations in all life domains. While the overall physical health score indicated substantial difficulties, the overall mental health score indicated minimal problems. The mean subscale scores and overall physical and mental health scores were significantly lower than population norms. The greatest areas of dysfunction were role functioning physical, physical functioning, vitality, and health perception, respectively.

Merkus et al. (1997) used the SF - 36 to assess the physical and mental health of hemodialysis and peritoneal dialysis patients who had been receiving treatment for three months. While participants evidenced substantial limitations in role functioning physical, mild to moderate limitations in functioning were also evident in all remaining life domains. The mean scores were significantly lower than population norms. The most problematic areas were role functioning physical, perceived general health, vitality, and physical functioning, respectively. The hemodialysis group had significantly more limitations in physical functioning, social functioning, role functioning emotional, and mental health, and more bodily pain and interference due to pain than the peritoneal dialysis group.

Diaz-Buxo et al. (2000) used the SF - 36 to examine aspects of physical

and mental health in hemodialysis patients. Overall physical and mental health scores were also reported. The findings indicated that participants experienced substantial limitations in role functioning physical and mild to moderate limitations in the remaining dimensions of health. Although overall physical and mental health scores were lower than population norms, most participants experienced moderate difficulties with their overall physical health, but only minimal overall mental health problems. In rank order, the four most problematic areas were role functioning physical, physical functioning, perceived general health, and vitality.

Kutner et al. (2000) used the SF - 36 to examine the physical and mental health of an incident cohort (i.e., approximately 60-days post-treatment initiation) of hemodialysis and peritoneal dialysis patients ($N = 236$). The Physical Activity Index (PAI) assessed functioning in terms of participation in sports or exercise, doing gardening or yard work, and taking walks. As well, five scales from the KDQOL (i.e., symptoms and problems, effects of kidney disease, burden of kidney disease, staff encouragement, and patient satisfaction) measured physical and mental health concerns. The KDQOL has been reported to be valid and reliable with the ESRD population (Edgell et al., 1996). The findings indicated that most study participants experienced mild limitations in physical activity, substantial limitations in their overall physical health, and minimal problems with their overall mental health. The only significant difference between the two dialysis groups was the greater physical activity reported by the

peritoneal dialysis group. Most participants scored significantly lower than the general population on all of the SF - 36 subscales. As well, substantial limitations were characteristic of the role functioning physical domain, and mild to moderate limitations for the other domains. Significantly, participants experienced the most difficulty with role functioning physical, perceived health, vitality, and physical functioning, respectively. Increased physical activity significantly correlated with better overall physical health, improved functioning and well-being as reflected by several SF - 36 domains (i.e., physical, social, mental health, vitality, bodily pain, and perceived general health), and a couple of KDQOL domains (i.e., fewer symptoms and problems and less illness burden).

Curtin et al. (2002) also used the SF - 36 to examine the physical and mental health of individuals receiving hemodialysis. The findings indicated that participants were experiencing substantial limitations in their overall physical health, but only minimal problems with their overall mental health.

Walters et al. (2002) used the KDQOL to examine aspects of physical and mental health in an incident hemodialysis population. The disease specific KDQOL assessed concerns related to physical and mental functioning and well-being. The mean subscale scores of the SF - 36 indicated that participants experienced mild to severe limitations in all eight life domains. Substantial limitations were noted in physical functioning, vitality, physical role functioning, and perceived health, respectively. While the overall PCS score indicated

moderate limitations in overall physical health, the mean MCS score suggested the group had excellent mental health. The mean subscale scores and overall physical and mental health scores were significantly lower than population norms.

Manns et al. (2002) used the KDQOL and the EuroQol EQ-5D to assess physical and mental functioning in a prevalent hemodialysis population. The EuroQol EQ-5D assessed five dimensions of functioning (i.e., mobility, self-care, usual activities, pain and discomfort, and anxiety and depression). The EuroQol EQ-5D also included a visual analog scale (VAS) that assessed overall HRQOL in terms of worst and best imaginable health states. All of the SF - 36 subscale scores were significantly below population norms, with substantial limitations noted for role physical functioning and moderate limitations for the remaining domains. Participants experienced the greatest difficulty with role functioning physical, perceived health, vitality, and physical functioning, respectively. With regard to the KDQOL items, the majority of participants had mild to moderate concerns with most dimensions (i.e., symptoms/problems, cognitive function, quality of social interaction, sexual function, social support, dialysis staff encouragement, satisfaction with care). The areas of the KDQOL that were most disconcerting for participants were work status, burden of kidney disease, sleep, and effects of kidney disease, respectively. Finally, the mean index score of the EuroQol EQ-5D and the mean EQ-5D VAS score suggested that most

participants enjoyed significantly less than optimal health and functioning and overall HRQOL, respectively .

Factors influencing HRQOL. A crucial step in providing interventions to enhance the QOL of the hemodialysis population is determining the effects of illness and treatment, social support, adjustment, medical risk factors, and demographic characteristics on outcome. Several studies were identified from the literature that investigated select aspects of different influencing factors. The following discussion presents a brief overview of study findings.

There were only a few studies that examined the association between indicators of HRQOL and illness and treatment experiences. In a subsequent analysis of the data received from a stable group of dialysis patients in the Parfrey et al. (1989) study, Barrett et al. (1990) found that greater physiological stressor severity significantly correlated with lower levels of overall physical and emotional functioning. Comparatively, Lok (1996) found that lower levels of physiological and psychosocial stressors were significantly related to greater overall functioning, as well as higher levels of social activities and improved life satisfaction. However, stressor levels failed to correlate with perceived physical activity levels.

Curtin et al. (2002) also investigated the degree to which physiological and psychosocial stressors correlated with overall physical and mental health. Following preliminary analysis, three summary indices (i.e., fatigue and sleep

index, sexual concerns index, and mobility index) were created from stressor items significantly correlating with overall physical and mental health. Four individual items (i.e., dry mouth, pruritus, lack of appetite, and restless legs) were also retained. In the final analysis, greater problems with fatigue and sleep, sexual relations, mobility, dry mouth, pruritus, and restless legs significantly correlated with worsening overall physical and mental health.

A few studies were also identified that explored the effects of social support on HRQOL. Tell et al. (1995) found that greater perceived social support demonstrated low, but significant, relationships with greater objective and subjective physical functioning, and fewer limitations in leisure activities. However, social network size failed to significantly correlate with either physical functioning or leisure activities.

In contrast to the Tell et al. (1995) study findings, Kimmel et al. (1996) failed to document a significant effect for either perceived overall support, satisfaction with dyadic relationships, or presence of a relationship on levels of physical functioning in either the incident or prevalent group. Similarly, Patel et al. (2002) failed to find a significant correlation between overall perceived support and levels of physical functioning.

Adjustment to and acceptance of the complexity of the ESRD and hemodialysis illness and treatment regime is key to achieving quality outcomes in this population. A review of the literature revealed several cross-sectional, but no

longitudinal, studies that examined the influence of variant aspects of adjustment (i.e., well-being and distress) on outcome.

Kimmel et al. (1995) and Kimmel et al. (1996) examined the association of psychosocial adjustment (i.e., vocational, extended family and sexual, and social) and depression with physical functioning in prevalent and incident groups. While greater social maladjustment significantly correlated with greater limitations in physical functioning in the prevalent group (Kimmel et al.,1995), greater vocational maladjustment significantly correlated with greater physical functioning limitations in the incident group (Kimmel et al., 1996). Extended family and sexual relations and depression levels failed to significantly correlate with physical functioning in either group.

Killingworth and Van Den Akker (1996) examined the effects of depression and adjustment on functioning levels. The findings indicated that greater depression and adjustment difficulties were significantly associated with greater difficulties with activities of daily living.

Lok (1996) investigated the influence of coping behaviors on functioning and well-being in individuals receiving hemodialysis. The findings revealed that less reliance on affective coping and greater reliance on problem-solving coping strategies were significantly related to greater overall functioning and well-being.

Walters et al. (2002) explored the correlation between depression and physical and mental health. Participants who scored positively for depression

reported significantly more limitations in physical functioning and role functioning physical, more bodily pain and interference due to pain, lower perceived health, greater interference with emotional well-being, greater limitations in role functioning emotional, greater interference with social functioning, and increased fatigue. As well, depressed participants also had significantly worse overall physical and mental health. With the exception of work status and perceived encouragement from hemodialysis staff, participants scoring positively for depression also had more concerns about symptoms and problems, kidney disease effects, the burden of kidney disease, cognitive impairments, less quality social interaction, sexual dysfunction, sleep interferences, reduced social support, and overall health. Multivariate analysis confirmed these findings.

Patel et al. (2002) examined the influence of depression levels on physical functioning. The study findings indicated that lower overall depression was significantly correlated with better objective physical functioning.

Medical risk factors have also been the focus of researchers examining correlates of HRQOL. In the literature reviewed, most researchers gave limited attention to these factors.

Kimmel et al. (1995) and Kimmel et al. (1996) examined the effects of illness severity, potassium, and phosphorus on the objective physical functioning of prevalent and incident populations, respectively. For both study populations, greater illness severity significantly correlated with increased limitations in

physical functioning. Although higher potassium levels significantly correlated with improved physical functioning in the prevalent group, neither potassium nor phosphorus were found to associate with physical functioning in the incident group.

Research findings were limited on the effects of length of time on dialysis and probability of hospitalization on the HRQOL of dialysis patients. Lok (1996) failed to document a significant association between time on dialysis and the functioning and well-being of individuals with regard to either their physical condition, social activities, or overall quality of life. However, DeOreo (1997) did find that study participants who had a greater probability of hospitalization tended to have greater limitations in their overall physical health.

Merkus et al. (1997) investigated the association of overall physical and mental health with several medical risk factors (i.e., co-morbid illnesses, protein catabolic rate, dialysis adequacy [urea reduction rate], hemoglobin, and albumin). Co-morbidity was defined in terms of the presence and total number of non-renal illnesses. Greater numbers of co-morbid illnesses were significantly correlated with greater limitations in physical functioning, social functioning, role functioning physical, mental health, vitality, bodily pain, and perceived health. While greater protein catabolic levels were significantly correlated with increased vitality, greater albumin levels were significantly related to improved physical functioning. Higher hemoglobin levels were significantly related to improved physical

functioning, greater social functioning, fewer limitations in role functioning emotional, improved mental health, increased vitality, and less bodily pain. Dialysis adequacy failed to demonstrate a significant relationship with any aspect of mental and physical health.

Kutner et al. (2000) examined the influence of select medical risk factors (i.e., blood urea nitrogen, creatinine, hematocrit, albumin, and dialysis adequacy) on overall physical and mental health in the dialysis population. Higher blood urea nitrogen was significantly related to improved vitality, fewer symptoms and problems, and fewer illness effects. Higher levels of pre-dialysis creatinine significantly correlated with better physical functioning and overall physical health. Higher hematocrit levels were significantly associated with better physical functioning, role functioning emotional, mental health, and overall physical and mental health. Greater albumin levels correlated significantly with better physical functioning. Finally, urea reduction rate was not a significant correlate of any study variables.

Manns et al. (2002) reported on the influence of dialysis adequacy on physical and mental health. Individuals who were more adequately dialyzed reported significantly better functioning in six of the SF - 36 domains (i.e., fewer limitations in physical functioning, better perceived health, fewer limitations in role functioning emotional, greater emotional well-being, less interference in social functioning, and increased energy). As well, individuals who were dialyzed more

adequately evidenced better functioning and well-being on disease specific (i.e., fewer sleep disturbances, fewer effects of kidney disease, and less burden of kidney disease), and generic (i.e., fewer limitations in mobility, self-care, normal activities, and less anxiety and depression) measures. Finally, participants who were more adequately dialyzed also reported better overall HRQOL.

Demographic characteristics was the final influencing factor grouping investigated with the hemodialysis population. In general, study findings revealed minimal to no correlations between demographic variables and the HRQOL of individuals receiving dialysis. Age, race, gender, and education have received the most attention.

Older age has been found to significantly correlate with greater limitations in physical functioning (Diaz-Buxo et al., 2000; Kimmel et al., 1995; Merkus et al., 1997; Patel et al., 2002; Tell et al., 1995; Walters et al., 2002), more limited overall physical health (Curtin et al., 2002; Diaz-Buxo et al.; Kutner et al., 2000; Walters et al.), greater overall mental health (Kutner et al.), less illness effects (Kutner et al.), and less staff encouragement (Kutner et al.). In contrast to Kutner et al., Merkus et al. found that older age was significantly associated with greater bodily pain and greater limitations in social functioning, role emotional, mental health, and vitality. Similarly, Walters et al. found that older was significantly correlated with less bodily pain, greater symptoms and problems, and greater social functioning.

With regard to race differences, Tell et al. (1995) found that black participants had better physical functioning and less leisure time restrictions than white participants. In contrast, Kutner et al. (2000) found that black participants reported had more role emotional limitations, worse mental health, worse overall mental health, and less satisfaction with care than non-blacks. In contrast to the findings by Kutner et al, Curtin et al. (2002) failed to document racial differences for overall mental health.

For the most part, gender was not found to influence physical functioning levels (Merkus et al., 1997; Patel et al., 2002; Tell et al., 1995), overall physical health (Curtin et al., 2002), or overall functioning (Klang & Clyne, 1997). Contrasting findings were reported by Kutner et al. (2002). Males had significantly greater vitality, less bodily pain, better overall physical health, fewer symptoms and problems, and less illness effects than females. Comparatively, Walters et al. (2002) found that women reported significantly more limitations in physical functioning, emotional well-being, vitality, and overall physical health status than males, but males reported significantly greater disability in sexual functioning than women.

The final factor, education level, also evidenced variant effects across studies. While Kutner et al. (2000) and Merkus et al. (1997) found that individuals with higher education experienced better physical functioning, Tell et al. (1995) failed to document such an effect. Counter to Kutner et al.'s findings,

Merkus et al. found that higher education levels were associated with greater role emotional functioning and better mental health. Kutner et al. found that participants with higher education reported greater illness burden but were also more satisfied with their care.

Summary

While there was limited consensus amongst researchers on the best operational measures for HRQOL, there was agreement on relevant indicators (i.e., functioning and well-being in various life domains, and health status). It was also apparent that different instruments assess different aspects of HRQOL. The suggestion that both generic and disease specific instruments be included in studies examining QOL needs to be further explored.

Importantly, study findings varied depending on the instruments used to collect data on HRQOL. When instruments other than the SF - 36 were used, the findings were indicative of mild functional limitations in most health domains. In contrast, SF - 36 scores varied from mild to severe across various health domains. Study findings were fairly consistent with regard to substantial limitations in overall physical health and minimal limitations in overall mental health. As well, study findings were similar on which health domains reflected the greatest limitations (i.e., physical functioning, vitality, physical role functioning, and perceived health).

With regard to factors influencing the HRQOL of hemodialysis patients, study findings were fairly consistent on the negative impact of physiological and psychological stressors. In contrast, conflicting findings were reported on the effects of social support, depression levels, and psychosocial adjustment. While the empirical evidence suggests that medical risk factors (i.e., biochemical parameters, comorbidity, and illness severity) are associated with functioning and well-being, more research is needed to ascertain the true nature and magnitude of the impact of these factors on HRQOL. Finally, the evidence suggested that demographic factors have minimal to no impact on the HRQOL of hemodialysis patients.

Discussion

Despite the chronic nature of ESRD and subsequent hemodialysis therapy, research findings suggest that these individuals exhibit an ability to adapt to the illness and rigid treatment regimes. Individuals with ESRD and receiving hemodialysis experience mild to moderate stressors and low levels of illness intrusiveness, assume responsibility for self-care activities, aspire to be informed about the illness and treatment, and experience low levels of illness severity. Although longitudinal studies are limited and use short time frames, most components of the illness and treatment experience remain relatively constant over time. There is also some evidence indicating that individuals

receiving hemodialysis are very satisfied with the quality of informal and informal supports, especially family, friends, and health care providers. While study findings indicate that most individuals were coping and adjusting well (i.e., low levels of distress and good well-being), there was also some evidence of adjustment difficulties. With most of the studies using cross-sectional designs, there is an obvious need for more longitudinal designs with longer time frames to further explore how perceptions of illness and treatment experiences, social support networks, and adjustment to a new normal change in response to variant health states and illness and treatment requirements.

Few studies were identified from the literature review that examined the interrelationships among factors defining the illness and treatment experience, social supports, and adjustment to a new normal. While study findings suggest that greater perceived satisfaction with overall support systems and dyadic relationships are related to lower levels of perceived illness intrusiveness, no support variables were found to correlate with illness severity. Furthermore, no studies were identified that examined the interrelationships among stressors, self-care, knowledge, and supports. Positive perceptions of illness and treatment experiences (i.e., stressor severity and illness intrusiveness) and social supports also seem to be important facilitators of adjustment to a new normal. Further longitudinal studies are needed to facilitate understanding of the interactive relationships among illness and treatment experiences, support networks, and

adjustment to a new normal.

Demographic and medical risk factors play a minor role in shaping illness and treatment experiences, satisfaction with informal and formal supports, and successful adjustment to a new normal. Significantly, study findings were inconclusive regarding the influence of demographic (e.g., age, gender, education, etc.) and medical risk factors (e.g., albumin, dialysis adequacy, phosphorus, time on hemodialysis, illness severity, etc.) on stressor severity, perceived illness intrusiveness, satisfaction with social supports and dyadic relationships, and levels of distress and well-being.

HRQOL was identified as an important endpoint in studies focusing on individuals with ESRD and receiving hemodialysis therapy. Longitudinal data on HRQOL (i.e., physical and mental health functioning) are limited and, sometimes, conflicting. Variations in study findings may be due, in part, to the different conceptual and operational approaches evident across studies. When researchers used instruments that assessed physical and emotional functioning (e.g., KS, SIP, CIWB, etc.) as outcomes of HRQOL, study findings indicated that participants were experiencing mild functional limitations. In contrast, when researchers assessed aspects of physical and mental health functioning using a combination of generic and disease specific instruments (e.g., SF - 36, KDQOL, etc.), study participants were found to have scores below population norms on all life domains, indicating mild to severe limitations in all aspects of functioning.

Significantly, study participants overall physical health scores were indicative of substantial limitations, but their overall mental health scores were close to normal levels.

While study findings are limited on key factors influencing the HRQOL of individuals receiving hemodialysis treatment, the evidence suggests that more positive illness and treatment experiences, greater satisfaction with social supports, and greater well-being and less distress correlate with higher levels of HRQOL. As with illness and treatment experiences, social supports, and adjustment levels, demographic and medical risk factors were found to exert variant and minimal effects on HRQOL.

Given the conceptual ambiguities and resulting operational variations surrounding the various constructs, it is essential that health care professionals develop a better understanding of key factors that influence illness and treatment, perceptions of social support, adjustment to a new normal, and quality outcome. Researchers need to expend greater efforts using longitudinal designs to examine how changes in key influencing factors can affect individuals' perceptions of these important constructs. This approach is essential for facilitating the identification of appropriate interventions that will help these individuals achieve optimal outcomes.

Conceptual Framework

Despite the developing research base on the effects of various illness and treatment factors, informal and formal supports, psychological and emotional states, and medical risk factors on quality outcome in the ESRD and hemodialysis population, most of this research has not been guided by disease-specific conceptual and theoretical frameworks. The LESRD-H model (see Figure 1) based on a grounded theory study of individuals' experiences with ESRD and hemodialysis (Gregory, 1998), represents one attempt to identify possible linkages among relevant factors believed to influence outcome.

The LESRD-H model proposes that it is possible to describe individuals' overall experiences with ESRD and hemodialysis in terms of three major interacting theoretical constructs (i.e., illness and treatment experiences, social supports, and adjustment to a new normal). Illness and treatment experiences refer to individual-specific reactions to physiological and psychosocial stressors. This construct also addresses a person's drive or motivation to become informed about ESRD and its treatment, as well as being actively involved in self-care practices (i.e., activities of daily living [ADL] and health management). The social support construct refers to individuals' satisfaction with formal and informal supports. Adjustment to a new normal refers to the person's ability to adapt to the emotional and psychosocial struggles resulting from the illness and treatment. The construct quality outcome is seen as the end result of the

separate and interactive effects of illness and treatment experiences, social supports, and adjustment indicators.

The LESRD-H model proposes that illness and treatment experiences and social supports directly influence adjustment to a new normal. It is also postulated that critical turning points (i.e., meanings attributed to episodic events that exert a separate and cumulative effect) link these constructs. In addition, illness and treatment experiences, social supports, and adjustment to a new normal exert a direct effect on quality outcome. Adjustment to a new normal mediates the impact of illness and treatment experiences and social supports on quality outcome.

In the current study, HRQOL (i.e., overall physical and mental health) is used as an indicator of quality outcome. One of the most comprehensive and frequently tested frameworks of health, functioning and well-being with the ESRD population is the Medical Outcomes Study's (MOS) conceptual framework. The MOS is based on patients' perceptions of outcome and includes three categories (i.e., structure, process, and outcome) (Tarlov et al., 1989). The structure variables (i.e., system, provider, and patient characteristics) are viewed as factors influencing process (i.e., technical and interpersonal aspects of practice styles) and outcome (i.e., disease-specific end-points, functional status, general well-being, and satisfaction with care). Process variables also influence outcome. The MOS framework identifies five indicators of physical and mental

health (i.e., clinical status, physical functioning and well-being, mental functioning and well-being, social and role functioning and well-being, and general health perceptions). Only limited aspects of the MOS framework (i.e., technical process of care, clinical end-points, and HRQOL) have been examined in the ESRD population (Rettig et al., 1997).

Definitions

The following definitions were used for the major constructs included in the LESRD-H model as defined by Gregory (1998) and Way, Parfrey, and Barrett (1998). .

Illness and treatment experiences. The illness and treatment experiences in the current study included individuals' perceptions of physiological stressors, ADL, confidence with illness and treatment knowledge, and self-health management. The four interrelated domains reflecting individuals' experiences were confirmed using exploratory factor analysis (Way et al., 1998).

Social supports. The particular aspect of social supports examined in the current study focused on individuals' perceptions of interactions with formal (i.e., nurses, physicians, and allied health professionals) and informal (i.e., family) networks. Special emphasis was placed on the perceived supportiveness of health care providers (i.e., technical, informational, and caring aspects) and the presence of reciprocal support within families. Exploratory factor analysis

also confirmed that four separate and interrelated factors defined the social support construct (Way et al., 1998).

Adjustment to a new normal. Adjustment to a new normal is defined in terms of losses and gains experienced by individuals with ESRD and undergoing chronic hemodialysis. This construct endeavors to capture how individuals adjust to negative and positive impacts in the social, psychological, emotional physical, and spiritual spheres. Exploratory factor analysis confirmed that two separate and interrelated factors (i.e., emotional well-being and psychosocial distress) comprised the adjustment construct (Way et al., 1998).

Critical turning points. Critical events in the current study are defined as impressionable moments that have variant effects depending upon the situational context. Critical events are attributed to the singular and cumulative effects of positive and negative events that occur over time (Gregory,1998).

Quality outcome. HRQOL was examined as the quality outcome in the current study. For the current purpose of this study, HRQOL is defined as health-related functioning in overall physical and mental health. Overall physical health captures limitations in physical functioning, physical role functioning due to physical health, bodily pain and interference due to pain, and perceived general health. Overall mental health captures limitations in general mental health, vitality, social functioning, and emotional role functioning due to problems in mental health.

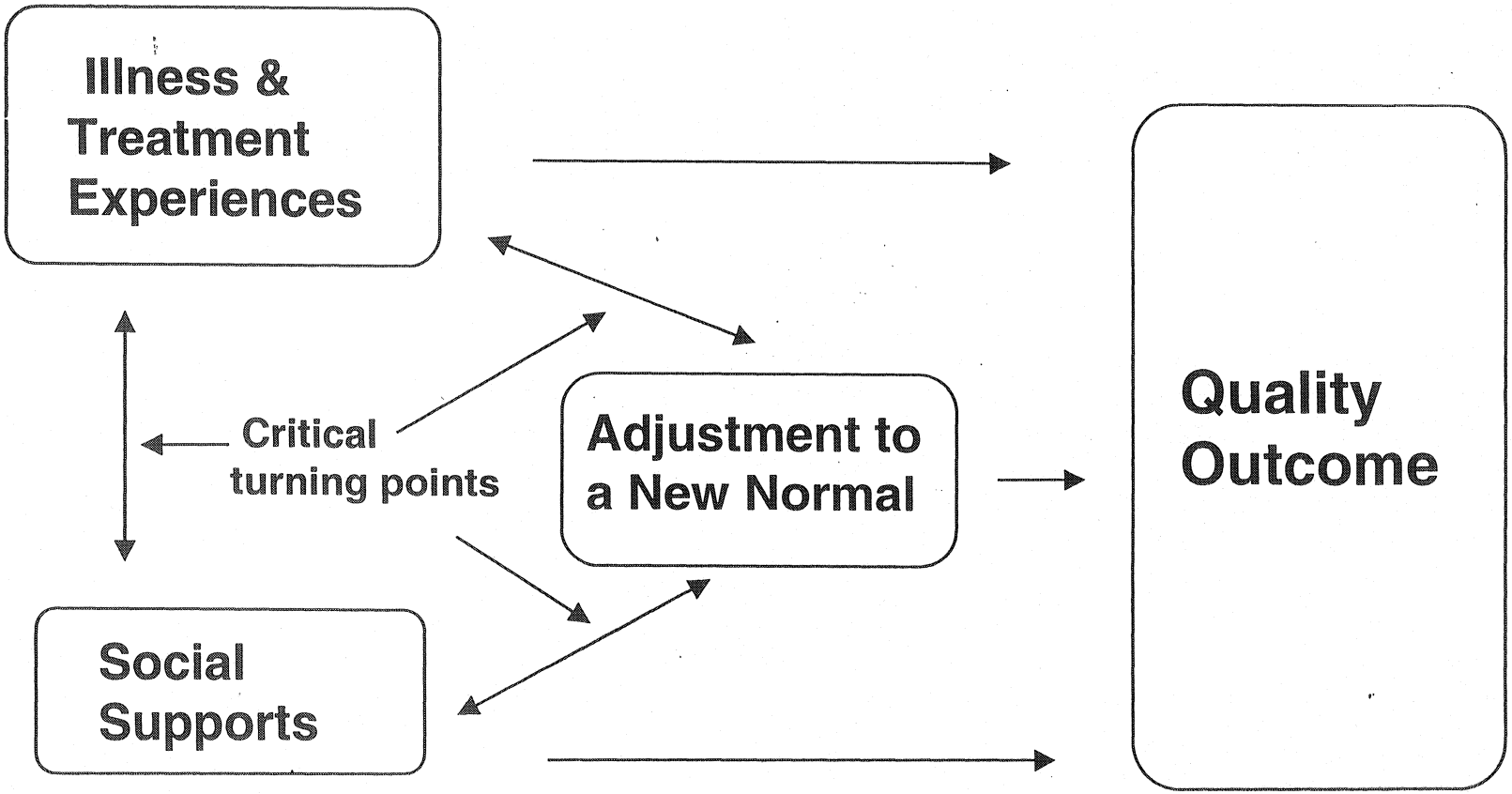

Figure 1. Living with End-Stage Renal Disease (ESRD) & Hemodialysis

Note: The model is based on the Proposed Model of Patients' Perceptions of their Experience with Hemodialysis as presented in "Patients' Perceptions of their Experience with End-stage Renal Disease and Hemodialysis Treatment" by Gregory (1998), Unpublished master's thesis, Memorial University of Newfoundland, St. John's, Canada.

CHAPTER 3

Methodology

A descriptive, correlational study with a repeated measures design was used to monitor changes in individuals' perceptions of illness and treatment experiences, quality of supports, and adjustment to a new normal over time. The relationships among major study variables (i.e., illness and treatment experiences, social supports, adjustment to a new normal, critical events, demographics, medical risk factors, and HRQOL) were examined. This chapter provides an overview of the population and sample, procedure, instruments, ethical considerations, and data analysis.

Population and Sample

Participants for the study were recruited from individuals receiving in-centre hemodialysis at four sites in Newfoundland and Labrador: Health Sciences Centre and Grace General Hospital of the Health Care Corporation of St. John's, Central West Health Care Centre in Grand Falls, and Western Memorial Regional Hospital in Corner Brook. Eligible participants were restricted to patients meeting the following criteria: (a) on hemodialysis for at least 12 weeks, (b) mentally competent to give informed consent, (c) English speaking, (d) 19 years of age or older, and (e) not experiencing any acute illness episode (e.g., acute renal failure or in a critical care setting), or a significant decline in

health as assessed by the attending nephrologist (e.g., terminal phase of dialysis, psychological maladjustment, etc.). A non-probability convenience sample was therefore obtained.

From the original convenience sample of 112 individuals interviewed at baseline, 72 met time-line requirements at 6 to 9 months. Only 44 of the 72 were available for a second interview (i.e., 61% response rate). The remainder were lost due to the following factors: failed to meet eligibility criteria (6), deceased (10), transplanted (6), or refused (6). An additional 16 patients were recruited for baseline and follow-up interviews, resulting in a total sample of 60.

Procedure

Data collection was initiated following ethical approval from the Human Investigation Committee, Faculty of Medicine, Memorial University of Newfoundland (see Appendix A) and the Research Proposal Approval Committee of the Health Care Corporation of St. John's (see Appendix B). A two phase procedure was used to collect data from the participants between December 1998 and July 1999. Initial contact was made by a registered nurse in each of the hemodialysis units who approached the patients to determine if they would be interested in participating in the study and to gain permission for a member of the research team to talk with them.

Potential participants were contacted by a member of the research team

and given a detailed explanation of the purpose of the study. Written consent was obtained following a complete explanation of the study and opportunity for questions (see Appendix C). A copy of the consent form was given to each participant. Face to face interviews were conducted during normally scheduled hemodialysis treatments. Each instrument was administered in the same order. At baseline, the demographic profile was completed first followed by the PPHS. At follow-up, the demographic profile, PPHS, SF - 36, and the critical events checklist, respectively, was completed. Follow-up interviews took place within 6 to 9 months ($M = 7$ months) after the initial interview. Interview time ranged from 60 to 90 minutes.

Instruments

Data were collected with five instruments: Baseline Personal Data Extraction Form, Patients' Perceptions of Hemodialysis Scale (PPHS), the Medical Outcomes Short Form - 36 (SF - 36), Follow-up Personal Data Extraction Form, and the Critical Events Checklist.

Baseline Personal Data Extraction Form

The baseline data extraction form (see Appendix D) was developed to collect data on demographic (i.e., age, gender, and living arrangements) and medical risk factors for ESRD (i.e., phosphorus, albumin, hemoglobin, urea

reduction rate, cause of ESRD, frequency and type of co-morbid illnesses, and illness severity).

Patient Perceptions of Hemodialysis Scale (PPHS)

The PPHS was developed by a research team from data collected from a qualitative study carried out with hemodialysis patients by Gregory (1998). The PPHS contains 64 items designed to assess individuals' perceptions of illness and treatment experiences, quality of social support, and adjustment to a new normal (see Appendix E). Drafts of the original PPHS were reviewed by the research team and modified to increase item clarity and decrease item redundancy. The final version was reviewed by an expert in adult literacy.

The final version of the PPHS is comprised of 64 items. Forty two items are worded in the negative and 22 are worded in the positive. The negatively worded items were reversed scored prior to entry into the statistical database. The rating scales for the items focus on frequency of occurrence of events or the degree of concern, satisfaction, or confidence perceived by individuals about the occurrence of events. Each item is rated on a Likert-type scale with scores ranging from 0 (*never or not at all*) to 4 (*almost always or extremely*). The possible score range was 88 to 168, with higher scores indicative of more positive attitudes towards the illness and treatment experience, greater perceived quality of social support, and greater adjustment to a new normal.

The original version of the PPHS was tested in a sample of patients receiving in-centre hemodialysis in St. John's, Newfoundland. Way et al. (1998) reported on the strong reliability and validity of the PPHS in preliminary testing. Construct validity was supported by the strong correlations between the major subscales and the total score (range: $r = .80$ - .94). As well, intercorrelations among the major subscales were positive and in the moderate to strong range (i.e., $r = .43$ to .67). Preliminary analysis revealed that internal consistency was high for the PPHS total score, with a alpha coefficient of .92. Slightly lower alpha coefficients were observed for each of the sub-scales (i.e., $r = .67$ to .89).

Medical Outcomes Study Short Form 36 (SF - 36)

The SF - 36 was completed at follow-up interview. The SF - 36 is a generic instrument developed using data collected from the Medical Outcome Study (MOS) and consists of eight sub-scales that measure functioning and well-being in various life domains (i.e., physical functioning, role functioning physical, bodily pain, general health, role functioning emotional, vitality, social functioning, and mental health) (see Appendix F). A physical component score (PCS), reflective of overall physical health status, is computed using the total sub-scale scores of physical functioning, physical role functioning, bodily pain, and general health scores. A mental component score (MCS), reflective of overall mental health status, is computed using the total sub-scale scores of role functioning

emotional, vitality, social functioning, and mental health.

Criterion and construct validity of this instrument has been documented (McHorney, Ware, Lu & Sherbourne, 1994). Median reliability coefficients were equal to or exceeded 0.80. Reliability has been assessed by both test-retest method and by internal consistency, and content validity of the various domains assessed by the SF - 36 compares favorably to that of other health status measures in common use (Rettig et al., 1997). Reliability of PCS and MCS summary measures in the general United States (US) population are reported as .93 and .88, respectively (McHorney et al., 1994).

Follow-up Personal Data Extraction Form and Critical Events Checklist

The follow-up personal data extraction form (Appendix G) was very similar to that used at baseline with the exception of the addition of data related to hospitalizations in the past six to nine months.

In addition, the critical events checklist (Appendix G) was used to assess the occurrence of critical events in the previous six to nine months. It was designed to measure any event that may affect the patients' ratings of major constructs in the model (i.e., illness and treatment experiences, social support, and adjustment). The data were collected using a yes/no response. The items on the instrument were based on the sub-scales of the PPHS (i.e., critical events related to illness and treatment experiences, social supports, and adjustment to a

new normal). Events were classified as negative or positive critical events.

Ethical Considerations

Ethical considerations were addressed in a number of ways. The study was approved by the Human Investigation Committee, Faculty of Medicine, Memorial University of Newfoundland and the Research Proposal Committee of the Health Care Corporation of St.John's. Approval to access the subjects was sought through the administration of all other health care facilities involved in the study.

Strict measures were taken to protect participants' rights. A registered nurse at each hemodialysis unit acted as intermediary between participants and the researcher. Prior to data collection, a complete explanation was given to each participant and an informed, written consent obtained. Potential participants were assured that their involvement was entirely voluntary and that they could withdraw at any time.

Confidentiality of all data and anonymity of participants were maintained throughout the study. Each subject was assigned a code number on entry into the study. This number was entered on each baseline interview and subsequent repeat interview. The master form identifying subjects name and number was kept in a locked filing cabinet accessible only to the researcher.

Data Analysis

Data were coded and entered into the SPSS for analysis. Descriptive statistics (e.g., frequencies, means, etc.) were used to generate a profile of illness and treatment, social support, and adjustment to a new normal (i.e., total PPHS and subscale scores), demographics (i.e., age and gender), and medical risk factors (i.e., time on hemodialysis, illness severity, number of co-morbid illnesses, urea reduction rate, albumin, hemoglobin, and phosphorus). Relationships between independent and dependent variables were determined using bivariate correlation coefficients. The ESRD scoring system was used to determine illness severity (Barrett et al., 1997). The illness severity score reflects a composite score based on age and the presence of co-morbid illnesses.

Paired *t* - tests were used to prospectively examine changes in total PPHS and sub-scale scores, biochemical parameters, illness severity, and number of co-morbid illnesses from initial interview to follow-up interview. Independent *t*-tests and/or ANOVA were used where appropriate to test for effects of select demographic and medical risk factors on the independent and dependent variables of interest and to determine differences in total PPHS and sub-scale scores, and PCS and MCS when examining critical events. The Bonferroni and/or Tamphane multiple comparison procedures were used to determine specific differences in group means. The alpha level was set at .05 for statistical significance.

CHAPTER 4

Results

Study findings are presented in three sections. The first section presents a descriptive profile of the sample and study variables. The second section describes the relationships among the variables under study. Finally, the reliability and validity of the PPHS and the SF - 36 are reviewed.

Descriptive Profile

This section presents an overview of the major study findings on key sample characteristics (i.e., demographic and medical risk factors). Finally, descriptive findings are presented on the total and subscale scores for the PPHS, critical events, and the SF - 36.

Demographics

Table 1 summarizes select demographic variables of the sample ($N = 60$). The majority of study participants were male (51.7%), living with a spouse (60%), and 50 years of age and older (68.4%). The mean age was 58.1 (± 17.84) years, with a range of 22 to 84 years.

Medical Risk Factors

The presentation of findings is restricted to the follow-up time period for

Table 1

Description of the Sample (N = 60)

Characteristic	*N*	%
Gender		
Male	31	51.7
Female	29	48.3
Living Arrangements		
Living with spouse	36	60.0
Living with another adult	13	21.7
Living with parents/children	5	8.3
Living in institution	1	1.7
Living alone	5	8.3
Age in Years		
<30	4	6.7
30 - 49	15	25.0
50 - 69	22	36.7
70 - 89	19	31.7

certain factors (i.e., causes of ESRD, length of time on dialysis, type of co-morbid illnesses, and the frequency and nature of hospitalizations during the study period). With regard to co-morbidity and biochemical parameters, where change in values could have important implications for participants' perceptions, both baseline and follow-up data are presented, as well as the significance of any changes between the time periods.

Table 2 summarizes study findings on select medical risk factors. The most frequently identified causes of ESRD were glomerulonephritis/autoimmune disorders (20%), diabetes (18.3%), and renal vascular disease (13.3%). Most participants had been on hemodialysis for three years or less, with a mean time of 23.2 months. The majority of participants had one or more co-morbid illnesses (61.7%), with diabetes (25%) and new onset or stable angina for greater than six months (25%) the most frequently reported illnesses. Finally, the majority of participants (56.7%) fell into the low risk illness severity category, indicating minimal effects of co-morbid illnesses.

Baseline and follow-up co-morbidity and biochemical data are presented in Table 3. There were no significant changes in the prevalence of co-morbid illnesses, t (59) = -0.41, p = .68, or illness severity, t (59) = -0.78, p = .44, between baseline and follow-up. Although the mean scores for hemoglobin, albumin, and phosphorus blood levels were within normal limits at baseline and follow-up, the urea reduction rate was slightly above the recommended minimal

Table 2

Select Medical Risk Factors at Follow-up (N = 60)

Variable	*N*	%
Cause of ESRD		
Glomerulonephritis/autoimmune	12	20.0
Diabetes	11	18.3
Renal vascular disease	8	13.3
Polycystic kidney disease	4	6.7
Congenital/hereditary disease	2	3.3
Other	23	38.3
Length of Time on Hemodialysis		
< 1 year	16	26.7
1 to 3 years	31	51.6
> 3 years	13	21.7
Number of Co-morbid Illness		
0	23	38.3
1 to 2	28	46.7
> 2	9	15.0
Type of Co-morbid Illnesses		
Diabetes	15	25.0
New onset/stable angina > 6 months	15	25.0
Congestive heart failure	13	21.7
Peripheral vascular disease	7	11.7
Lung disease	6	10.0
Stroke	5	8.3
Cancer	4	6.7
Unstable angina < 6 months	4	6.7
Arrhythmia	3	5.0
Illness Severity		
0 to 4	34	56.7
5 to 9	24	40.0
> 9	2	3.3

Table 3

Co-morbidity and Biochemical Parameters at Baseline and Follow-up (N = 60)

Variable	*Baseline* *M (SD)*	*Follow-up* *M (SD)*	*r*	*t*
Co-morbidity				
# of Co-morbid Illnesses	1.15 (1.22)	1.20 (1.29)	.72***	-0.41
Illness Severity	3.95 (2.38)	4.10 (2.66)	.83***	-0.78
Biochemical Parameters				
Hemoglobin	112.02 (17.04)	116.94 (14.80)	.28*	-1.98
Albumin	34.85 (5.15)	36.05 (4.13)	.77***	-2.82**
Urea Reduction Rate	68.48 (6.46)	70.92 (5.35)	.66***	-3.79***
Phosphorus	2.01 (.58)	1.96 (.56)	.64***	0.71

*$p < .05$. **$p < .01$. ***$p < .001$

level of 65% (National Kidney Foundation, 2000). While no significant differences were observed in hemoglobin and phosphorus values over time, significant improvements were noted in albumin levels, t (59) = -2.82, p = .007, and the urea reduction rate, t (59) = -3.79, p = .000.

Table 4 presents the findings on the frequency of and reason for hospitalizations, as well as the admitting diagnoses, during the data collection period (i.e., 6 to 9 months). The majority of participants (65%) were not hospitalized. Of those who were hospitalized (n = 21), most participants (52.4%) experienced only one admission. The most frequent reason for admission was for a health problem unrelated to ESRD (76.2%).

Perception of ESRD and Hemodialysis

Individuals' perceptions of ESRD and hemodialysis were comprised of three major content domains: illness and treatment experiences (i.e., frequency of physiological stressors, satisfaction with performance of ADL, confidence with illness and treatment knowledge, and involvement in self-health management), social supports (i.e., satisfaction with family, nurses, physicians, and allied health professionals), and adjustment to a new normal (i.e., levels of emotional well-being and psychosocial distress). Baseline and follow-up weighted mean scores and standard deviations for major and minor subscales and the total PPHS are

Table 4

Hospitalizations and Admitting Diagnosis (N =60)

Variable	*N*	%
Hospitalizations Between Baseline and Follow-up		
No	39	65.0
Yes	21	35.0
Admission Frequency for those Hospitalized		
1	11	52.4
2	7	33.3
≥3	3	14.3
Reason for Admission		
Illness unrelated to ESRD	16	76.2
ESRD related	5	23.8

summarized in Table 5. In general, higher scores are indicative of more positive attitudes. The exceptions are physiological stressors and psychosocial distress, with higher scores reflecting less frequent stressors and less distress. Table 6 summarizes the mean change scores between baseline and follow-up, as well as the paired *t* - test results.

At both baseline and follow-up, the majority of study participants had positive perceptions of ESRD and hemodialysis. While the rank ordering varied slightly over time, participants were most positive about nurses' support, self-health management, and physician support. In contrast, participants were most negative about physiological stressors, performance of ADL, and psychosocial distress. For the most part, PPHS subscale scores were comparable over time. The only significant differences were in decreased satisfaction with family support, $t\,(59) = 3.12$, $p = .003$, and decreased involvement in self-health management, $t\,(59) = 2.37$, $p = .021$, at follow-up.

In order to facilitate a greater appreciation of participants' perceptions, detail is presented on individual items comprising the PPHS. The following presentation of findings is organized according to the major subscales of the PPHS. The percentage of positive and negative responses reflect a collapsing of the scale steps into low (*never or not at all and rarely or a little bit*) and moderate to high (*sometimes or moderately, often or quite a bit, and almost always or extremely).*

Table 5

Weighted Mean Scores of Perception of ESRD and Hemodialysis (N = 60) [a] ***at Baseline and Follow-up***

Subscales	Baseline *M*[b] *(SD)*	Follow-up *M*[b] *(SD)*
Illness/Treatment Experiences	2.50(.43)	2.47(.37)
Physiological Stressors	2.14(.68)	2.16(.59)
Performance of Activities of Daily Living	2.37(.86)	2.50(.85)
Knowledge	2.57(.86)	2.63(.67)
Self-Health Management	3.18(.70)	2.91(.86)
Social Supports	3.15(.56)	3.08(.44)
Family	2.97(.91)	2.63(1.05)
Nurses	3.36(.59)	3.30(.53)
Physicians	3.08(.84)	3.09(.70)
Allied Health Professionals	2.86(.92)	2.79(.98)
Adjustment to a New Normal	2.68(.65)	2.63(.62)
Emotional Well-Being	2.89(.62)	2.84(.65)
Psychosocial Distress	2.48(.84)	2.46(.87)
Total Patient Perceptions of Hemodialysis Scale	2.75(.45)	2.69(.37)

[a] Sample size for each subscale varies with the amount of missing data.

[b] Raw Scores were summed and divided by subscale item totals. The rating scale for the subscales ranged from 0 to 4, with a mean of 2.

Table 6

Mean Change Scores Between Baseline and Follow-up and Paired t - Test Results of Perception of ESRD and Hemodialysis (N = 60) [a]

Subscales	Mean Change Scores	*SD*	*r*	*t*
Illness/Treatment Experiences	-.01	.39	.52***	0.19
Physiological Stressors	.04	.63	.53***	-0.50
Performance of ADL	.13	.95	.38**	-1.04
Knowledge	.06	.80	.47***	-0.56
Self-Health Management	.54	1.29	.39**	2.37*
Social Supports	-.10	.38	.72***	1.86
Family	-.34	.84	.64***	3.12**
Nurses	-.06	.50	.61***	0.94
Physicians	.01	.71	.59***	-0.07
Allied Health	-.03	.97	.44**	0.22
Adjustment to a New Normal	-.03	.39	.80***	0.54
Emotional Well-Being	-.04	.48	.71***	0.59
Psychosocial Distress	-.02	.53	.81***	0.28
PPHS Scale	-.03	.28	.80***	0.76

[a] Sample size for each subscale varies with the amount of missing data.

*$p < .05$. **$p < .01$. ***$p < .001$.

Note. ADL = Activities of Daily Living. PPHS = Patient Perceptions of Hemodialysis Scale.

Illness and treatment experiences. Overall, most participants had positive attitudes toward the illness and treatment at baseline and follow-up (M = 2.50 and 2.47, respectively). Study findings are organized according to each subscale of this construct, with accompanying weighted means and percentages for individual items for both time periods (i.e., first baseline and then follow-up).

The physiological stressor scores (M = 2.14 and 2.16) suggested that participants were sometimes bothered by physiological stressors. On the positive side, most participants felt comfortable after dialysis (75% and 73.4%) and never or rarely experienced breathing difficulties (66.6% and 70%). In contrast, most participants indicated that they usually felt tired and low on energy (83.4% and 68.3%), felt exhausted after dialysis (80% and 71.6%), experienced hypotension during or after dialysis (71.7% and 73.4%), and were bothered by walking short distances (57.6% and 52.5%). A significant percent also experienced muscle cramps during or after dialysis (56.6% and 46.7%) and itching (46.7% and 55%).

The performance of ADL scores (M = 2.37 and 2.50) indicated that most participants were moderately satisfied with their ability to perform ADL. Specifically, most participants were satisfied with their ability to assume self-care responsibilities (88.3% and 93.3%) and do household and work activities (66.7% and 80.1%), and often participated in recreation activities (61.7% and 63.3%).

The knowledge scores indicated that participants were moderately

confident with their understanding of the illness and treatment (M = 2.57 and 2.63). The majority of participants were quite satisfied with the information received about the benefits and side effects of dialysis (90% and 91.7%). As well, most participants were confident that they understood why diet and fluid restrictions were required (88.3% and 95%), about what caused the loss of their kidney function (63.3% and 71.6%), and about requirements for a kidney transplant (60.1% and 56.7%).

The self-health management scores (M = 3.18 and 2.91) indicated that participants were often involved in managing their own health. Most participants usually informed the nurse about problems when they occurred (93.3% and 80%), monitored nurses' activities during dialysis (89.9% and 88.3%), followed diet and fluid restrictions (85% and 90%), and watched for problems during dialysis (81.7% and 63.4%). As noted previously, there was a significant decline in self-health activities over time. Individual scale items indicated significant reductions in reported frequencies of informing nurses about emerging problems ($p < .01$), as well as vigilant activities ($p < .05$), during dialysis.

Social supports. Overall, most study participants were satisfied with their informal and formal supports at both baseline and follow-up (M = 3.15 and 3.08, respectively). Study findings are organized according to each major content domain of this construct, with relevant weighted means and percentages for individual items for both time periods (i.e., first baseline and then follow-up).

The family support mean scores (M = 2.97 and 2.63) suggested that most participants were quite satisfied with this form of support. Specifically, the majority of participants felt that family members helped facilitate acceptance of illness and treatment requirements (88.3% and 83.4%), and reminded them about diet, fluid, and activity restrictions (73.3% and 71.7%). Finally, most participants reported that they often tried to lessen the impact of the illness and treatment on family members (86.6% and 68.3%). As noted previously, there was a significant decline in perceived family support over time. Individual scale items indicated significant reductions in participants' perceptions of how often family members helped facilitate acceptance of illness and treatment requirements ($p < .05$) and how often they did things to help lessen the impact of the illness and treatment on family members ($p < .01$).

With regard to formal supports, most participants were quite a bit to extremely satisfied with the support received from nurses (M = 3.36 and 3.30). All of the participants were satisfied with the overall quality of nursing care, and were confident that nurses had the necessary knowledge and abilities to know what to do if they became ill on hemodialysis. As well, the majority of participants were satisfied with nurses' comfort measures (98.3% and 96.6%), nurses' willingness to listen to them (96.6% and 95%), and the time spent by nurses to help them understand illness and treatment requirements (96.7% and 91.6%). In addition, most participants felt that nurses tried to promote a relaxed family like atmosphere in the hemodialysis unit (86.7% and 93.4%), were not

concerned that nurses might be too busy to pay attention to them during dialysis (76.6% and 81.7%), and rarely experienced delays in receiving scheduled treatments (70% and 75%).

The physician support scores (*M* = 3.08 and 3.09) suggested that participants were quite satisfied with this form of support. Specifically, the majority of participants were satisfied with the overall quality of medical care (96.7% and 96.7%), and were confident that physicians had the necessary knowledge and abilities to monitor or deal with overall physical needs (93.3% and 95.1%). As well, most participants were satisfied with the quickness of physicians' response to their needs while on hemodialysis (91.7% and 96.7%), physicians' willingness to listen to them (88.3% and 93.4%), and the time spent by physicians helping them understand illness and treatment requirements (83.3% and 88.4%).

Finally, most participants were moderately to quite satisfied with the support provided by allied health professionals (*M* = 2.86 and 2.79). Specifically, most participants (89.4% and 75.4%) were satisfied with social workers' helpfulness with illness and treatment problems, and the information provided by dieticians (86.7% and 89.9%).

Adjustment to a new normal. The overall mean scores for the adjustment subscale suggested that most participants viewed the self positively at baseline and follow-up (*M* = 2.68 and 2.63, respectively). Study findings are organized according to the major factors comprising this construct, with

accompanying weighted means and percentages for individual items for both time periods (i.e., first baseline and then follow-up).

The emotional well-being mean scores (M = 2.89 and 2.84) indicated that participants were adjusting well emotionally. On the positive side, the majority of participants felt that they had accepted dialysis as a normal part of life (100% and 98.3%), felt that they were coping well with dialysis restrictions (98.4% and 91.6%), tried to maintain a positive attitude toward dialysis (95% and 95%), were satisfied with how well they had adjusted to dialysis (91.7% and 95%), felt relaxed during dialysis (91.6% and 95%), and felt good about the closeness among fellow patients during dialysis (91.6% and 85%). As well, most participants believed that dialysis had improved their QOL (86.7% and 75%), felt they spend quality time with family and friends (83.3% and 91.7%), were confident that they would come to terms with their illness (80.1% and 83.3%), felt in control of the ups and downs of dialysis and its effects on health and well-being (78.3% and 76.7%), felt stronger as a person due to their illness (71.6% and 66.1%), and believed that it was possible to manage the financial costs resulting from hemodialysis (68.4% and 75%).

The psychosocial distress scores (M = 2.48 and 2.46) indicated that most participants experienced low to moderate distress. On a positive note, the majority of participants were not concerned for their personal safety while on dialysis (76.6% and 75%), or about voicing their needs to nurses or physicians due to the physical closeness of others during dialysis (76.7% and 65%). In

addition, most participants rarely dwelt on their own health problems after the death of fellow patients (71.7% and 73.3%), got upset by seeing other patients become ill (61.7% and 60%), or experienced fears or worries about unexpected events (53.3% and 60%). On the negative side, most participants were concerned about the impact of the illness and treatment on family members (75% and 60%), what could happen if they failed to follow recommended diet and fluid restrictions (68.4% and 60%), and becoming too dependent on their families (58.3% and 55%). As well, a slight majority of participants reported feeling useless due to their dependance on others (55% and 53.3%) and so frustrated with things that they wanted to come off the machine and go home (53.4% and 60%). A significant number were overwhelmed by the severity of the illness and long-term treatment requirements (53.3% and 46.7%), concerned that their health would get worse regardless of what they or the doctors did (40% and 53.3%), and felt depressed about their illness and long-term treatment requirements (48.4% and 55%).

Critical Events

Critical events included positive and negative occurrences within each major category (i.e., illness and treatment experiences, social supports, and adjusting to a new normal) between baseline and follow-up. The findings indicated that study participants, in general, reported more positive than negative events across the categories (see Table 7). An equally important observation

was the high consistency of subject responses within each major category (e.g., subjects with negative illness events more often than not failed to report positive events, and vice versa, etc.). The presentation of findings is organized according to each major category.

Illness and treatment experiences. This category consisted of important illness and treatment events that could have positive or negative repercussions for participants. With regard to illness experiences, most participants reported having experienced positive events (78.3%). Positive experiences were significantly more likely to emanate from a predictable illness course (i.e., stable physical functioning) (63.3%). A much smaller percent of participants reported an improvement in health status and well-being (38.3%), positive reinforcement from greater availability of alternate treatment modalities (21.7%), increased motivation to follow recommended lifestyle changes (16.7%), and improved renal function (6.7%).

A significant percent of participants also experienced negative illness events (60%). Negative illness events were significantly more likely to be associated with an unpredictable illness course (i.e., variable levels of physical functioning) (38.3%), further loss of renal function (25%), and declining health status and well-being (18.3%). A much smaller percent experienced decreased motivation to follow recommended lifestyle changes (10%) and decreased availability of alternate treatment modalities (1.7%).

Table 7

Nature of Critical Events Between Study Period (N = 60)

Variable	*N*	%
Positive illness events		
Present	47	78.3
Absent	13	21.7
Negative illness events		
Present	36	60.0
Absent	24	40.0
Positive treatment events		
Present	60	100.0
Absent	0	0.0
Negative treatment events		
Present	51	85.0
Absent	9	15.0
Positive support events		
Present	60	100.0
Absent	0	0.0
Negative support events		
Present	41	68.3
Absent	19	31.7
Positive self events		
Present	60	100.0
Absent	0	0.0
Negative self events		
Present	42	70.0
Absent	18	30.0

With regard to treatment-related experiences, all of the participants (100%) reported positive events. The majority of participants indicated that they felt good while receiving dialysis (76.7%), had a well-functioning dialysis access site (75%), and did not experience transportation problems for dialysis (68.3%). A smaller percent experienced improved physical functioning following dialysis treatment (43.3%) and were satisfied with the time spent receiving dialysis treatment (33.3%).

Although most participants (85%) reported negative treatment events, there was not as much clustering as with positive treatment events. A significant percent of participants reported feeling unwell during dialysis (45%), experiencing problems with their access sites (38.3%), and feeling unhappy with the time spent receiving dialysis treatment (35%). A smaller percent of participants experienced decreased physical functioning following dialysis treatment (21.7%), and had transportation problems to the dialysis site (20%).

Social supports. In the supports category, consideration was given to critical events occurring with informal (i.e., family and friends) and formal (i.e., nurses and physicians) supports, as well as the dialysis environment (i.e., relations with dialysis peers and overall satisfaction with the environment). Significantly, all of the participants reported positive experiences with their supports. Specifically, the vast majority of participants reported a positive social environment (96.7%) and strong family supports (95%). As well, most participants had trust and confidence in nurses (95%) and physicians (95%).

Finally, most participants indicated they had a good rapport with dialysis peers (96.7%), and were satisfied with the dialysis environment (76.7%).

The majority of participants (68.3%) also highlighted negative experiences with supports. Most participants reported losing dialysis peers (56.7%). As well, a significant percent experienced decreased satisfaction with the dialysis environment (21.7%), loss of friendship networks (18.7%), and loss of family members (11.7%). Only a small percent of participants experienced reduced trust and confidence in physicians (6.7%) and nurses (3.3%).

Adjustment to a new normal. As with the illness and treatment experience and social support categories, there was some overlap in how participants rated areas of impact. That is, upon reflection, some participants could identify both positive and negative experiences associated with specific events or feeling states.

All of the participants experienced positive events, although variations were observed across the indicators. Specifically, most participants had positive attitudes toward the illness and treatment (88.3%), felt hopeful (81.7%), were content with independent living (80%), were satisfied with social activities (68.3%), felt in control of life events (61.7%), reported no to minimal impact on their financial security (58.3%), and were satisfied with their health and QOL (56.7%). As well, a significant percent of participants reported an increased sense of self-worth (43.3%).

In contrast, most participants (70%) reported experiencing negative

changes to their sense of self. As well, a significant proportion of participants experienced uncertainty and stress in relation to their health and QOL (48.3%), and were dissatisfied with their level of social activities (40%). A smaller percent of participants reported feeling less in control over life events (28.3%), a sense of hopelessness (26.7%), a negative attitude toward the illness and treatment (20%), a loss of independence (16.7%), threats to their financial security (11.7%), and a decreased sense of self-worth (6.7%).

Short Form 36 (SF - 36) at Follow-up

The SF - 36 health survey assesses eight dimensions of functioning and well-being (i.e., physiological functioning, role functioning physical, bodily pain, general health, vitality, social functioning, role functioning emotional, and mental health). With raw scores transformed by specified weighted factors, the possible score range for the eight subscales is 0 to 100. The scales were also further compressed into two dimensions (i.e., PCS and MCS), with normalized scores ranging from 0 to 50. Higher scores are indicative of better functioning in all instances. The means and standard deviations for the SF - 36 subscales and the overall PCS and MCS are presented in Table 8.

Physical Functioning (PF). This scale assesses both the presence and severity of physical limitations in performing certain activities. The mean score

Table 8

SF - 36 Scale Scores and PCS and MCS Scores at Follow-up (N = 60) [a]

Variable	Current Study *M* (*SD*)	General U.S. Population *M* (*SD*)
Physical Functioning	52.42 (26.96)	84.20 (23.30)
Role Functioning Physical	53.33 (40.25)	81.00 (34.00)
Bodily Pain	65.98 (29.15)	75.20 (24.00)
General Health	43.77 (22.58)	72.00 (20.00)
Vitality	50.92 (24.57)	60.80 (21.00)
Social Functioning	74.17 (31.80)	83.30 (22.70)
Role Functioning Emotional	80.56 (34.87)	81.00 (33.00)
Mental Health	78.00 (21.50)	74.70 (18.10)
PCS	35.91 (9.66)	50.0 (10.00)
MCS	53.33 (11.35)	50.0 (10.00)

Note: PCS = Physical Component Score. MCS = Mental Component Score.

[a] Sample size is a function of missing data.

(M = 52.42) was much lower than population norms (see Table 8), suggesting that most participants experienced substantial limitations in physical functioning. Although most participants (81.7%) reported being limited a lot while performing vigorous activities (e.g., running, lifting heavy objects, etc.), they were divided on the extent to which their health limited other activities. Specifically, a significant percent of participants reported being limited a lot in walking more than a mile, performing moderate activities (e.g., moving a table, pushing a vacuum cleaner, etc.), climbing several flights of stairs, and walking several blocks (i.e., 50%, 48.3%, 46.7%, and 46.7%, respectively). In contrast, most participants reported little or no difficulty with bathing or dressing (93.3%), climbing one flight of stairs (88.3%), bending, kneeling, or stooping (78.3%), walking one block (80%), and lifting or carrying groceries (73.3%).

Role Functioning Physical (RP). This scale assesses the degree to which physical role functioning changed over the previous four weeks. As shown in Table 8, the mean score (M = 53.33) for physical role functioning was much lower than population norms. This low score is indicative of study participants' perceptions of substantial difficulties in performing work or other regular daily activities due to their physical health. Specifically, a slight majority of participants reported accomplishing less than desired (55%), being limited in the kind of work or activities performed (53.3%), and experiencing difficulty performing work or other activities (51.7%). In contrast, most participants (73.3%) had not reduced the amount of time spent on work or other activities.

Bodily Pain (BP). This scale is used to assess changes in the perceived severity of bodily pain and the extent to which it interfered with normal activities over the previous four weeks. The mean score ($M = 65.98$) for the bodily pain scale was below population norms (see Table 8). The findings suggest that most participants experienced mild pain and minimal interference with normal work. Specifically, the majority of participants reported mild to no pain in the previous four weeks (63.4%) and minimal to no interference with normal work (71.7%).

General Health (GH). This scale assesses perceived health status. The mean score ($M = 43.77$) for the study population was substantially lower than population norms (see Table 8). Study findings suggest that participants perceived their health to be less than optimal. The majority of participants (63.3%) rated their overall health as being good to very good. On the negative side, most participants viewed themselves as being less healthy than other people (68.3%), and did not consider their health to be excellent (76.7%). As well, a significant number of participants believed that they got sicker easier than other people (43.3%), and expected their health to get worse (46.7%).

Vitality (VT). The VT scale is used to assess changes in energy levels over the previous four weeks. Again the mean score ($M = 50.92$) for the study population was below population norms (see Table 8). Study findings suggest that participants experienced moderate impairments in this area. Specifically, the majority of participants reported not feeling full of pep (61.7%) or having lots

of energy (68.3%) most of the time. However, only about one-half of participants reported feeling worn out or tired a little bit or some of the time.

Social Functioning (SF). This scale assesses the extent and amount of time that physical health or emotional problems interfered with social activities with family, friends, neighbors, or groups over the previous four weeks. Although the mean score ($M = 74.17$) for study participants was lower than population norms (see Table 8), it reflected minimal interferences with social activities. For the majority of participants (73.3%), physical and/or emotional problems had no to slight interference with normal social activities. As well, most participants (61.7%) reported that physical and/or emotional problems only interfered infrequently with social activities.

Role Functioning Emotional (RE). This scale assesses the degree to which emotional problems interfered with normal work or activities over the previous four weeks. The mean score ($M = 80.56$) was comparable to that obtained from normal populations (see Table 8), indicating that emotional problems had limited effects on normal work or other activities. Specifically, the majority of participants had not reduced the amount of time spent on work or other activities (83.3%), performed work or other activities less carefully than usual (81.7%), or accomplished less than desired (76.7%).

Mental Health (MH). This scale assesses feelings of anxiety and depression over the previous four weeks. The mean score ($M = 78.00$) was

slightly above population norms (see table 8), suggesting that most participants experienced minimal nervousness or depressed feelings. Specifically, the most participants indicated that they rarely felt nervous (83.3%), so down in the dumps that nothing could cheer them up (73.3%), or downhearted and blue (66.7%). Similarly, most participants reported feeling happy (76.7%) and calm and peaceful (70%) most of the time.

PCS and MCS. While the PCS is reflective of overall physical and general health, the MCS refers to a person's overall mental health. The mean PCS ($M = 35.91$) was below population norms (see Table 8) and is reflective of substantial limitations in self-care and role activities, some bodily pain and tiredness, and less than optimal physical health. The mean MCS ($M = 53.33$) was slightly above norms for the general population (see table 8), indicating that study participants considered themselves to be in excellent mental health, were not experiencing any psychological distress, had minimal social or role limitations due to emotional problems, and rated their health from good to very good.

Interrelationships Among Study Variables

This section examines the relationships among key influencing and outcome variables. The first two subsections present the findings on the effect of demographic variables (i.e., gender, living arrangements, and age) and medical risk factors (i.e., length of time on hemodialysis, frequency of co-morbid illness and hospitalizations, illness severity, and biochemical parameters) on major

study variables (i.e., perception of ESRD and hemodialysis and HRQOL). The third and fourth sections examine the effect of critical events on major study variables. The remaining sections address the interrelationships among major study variables.

ESRD and Hemodialysis with Demographics and Medical Risk Factors

Overall, demographics and medical risk factors exerted minimal effects on individuals' perceptions of ESRD and hemodialysis at both baseline and follow-up. The following discussion reviews the specific areas of impact, and highlights the differences across the time periods.

Demographic variables. Gender was not associated with any of the variables at either time period. Age was observed to exert minimal effects. Older participants were less confident than younger ones with illness and treatment knowledge at baseline, $r = -.33$, $p = .010$, and follow-up, $r = -.42$, $p = .001$. As well, older participants experienced less psychosocial distress at baseline, $r = .43$, $p = .001$, and follow-up, $r = .30$, $p = .020$, than their younger counterparts. Older participants were also more satisfied with support from physicians at baseline, $r = .264$, $p = .042$, than their younger counterparts. While living arrangements did not influence any of the study variables at baseline, there was some impact at follow-up. Specifically, individuals living with a spouse had significantly less physiological stressors, $t(57) = 2.58$, $p = .013$, and were more

satisfied with family supports, $t(38.95) = 2.13$, $p = .04$, than those in other living arrangements.

Medical risk factors. Hemoglobin, albumin, and the presence or absence of hospitalization were not significantly associated with any of the variables at either baseline or follow-up. In contrast, increased length of time on hemodialysis was significantly associated with decreased satisfaction with nursing support at baseline, $r = -.29$, $p = .025$, and follow-up, $r = -.36$, $p = .005$, and greater psychosocial distress at baseline, $r = -.38$, $p = .003$, and at follow-up, $r = -.35$, $p = .006$.

Significantly, there were a few notable inconsistencies over time in the influence of other medical risk factors on select aspects of individuals' perceptions of ESRD and hemodialysis. The spurious findings may be due to the multiple analyses and borderline *p* values. At baseline, participants with greater illness severity were significantly more likely to be less confident with their illness and treatment knowledge, $r = -.33$, $p = .011$, and evidence less psychosocial distress, $r = .26$, $p = .048$, than those with less illness severity. At follow-up, while psychosocial distress failed to achieve statistical significance with illness severity, physiological stressors became a significant correlate and confidence with knowledge continued to depict a significant relationship. Specifically, participants with greater illness severity were significantly more likely to report greater physiological stressors, $r = -.29$, $p = .026$, and to be less

confident with their illness and treatment knowledge, $r = -.31$, $p = .015$, than those with less illness severity. Finally, increased time on hemodialysis was significantly correlated with less involvement in self-health management at baseline, $r = -.26$, $p = .045$, however, this relationship had disappeared at follow-up.

As well, number of co-morbid illnesses failed to influence any variables at baseline. However, at follow-up, participants who had a greater number of co-morbid illnesses were significantly more likely to experience an increased frequency of physiological stressors, $r = -.33$, $p = .012$, than those with fewer co-morbid illnesses.

With regard to the biochemical parameters at baseline, greater urea reduction rate was associated with better emotional well-being, $r = .27$, $p = .038$. As well, greater phosphorus levels were associated with less satisfaction with performing ADL, $r = -.35$, $p = .007$, and less satisfaction with AHP, $r = -.28$, $p = .033$. However, all of these associations disappeared at follow-up.

HRQOL with Demographics and Medical Risk Factors

The discussion in this section is restricted to the association of demographic and medical risk factors with overall physical and mental health at follow-up. The SF - 36 assessed overall physical and mental health. None of the demographic variables (i.e., age, gender, and living arrangements) were

significantly associated with overall physical and mental health. As well, phosphorus, urea reduction rate, hemoglobin, illness severity, and hospitalization were not associated with overall physical and mental health. However, other medical risk factors (i.e., number of co-morbid illnesses, length of time on hemodialysis, and albumin) significantly correlated with overall physical health, but not overall mental health. Specifically, participants with more co-morbid illnesses, $r = -.29$, $p = .026$, on dialysis for longer periods of time, $r = -.36$, $p = .005$, and with lower albumin levels, $r = .47$, $p = .000$, were significantly more likely to experience poorer overall physical health than those with fewer co-morbid illnesses, on dialysis for shorter periods of time, and higher albumin levels.

Perception of ESRD and Hemodialysis and Critical Events

The findings revealed few significant differences in participants' perceptions of ESRD and hemodialysis at follow-up based on critical events. With all participants reporting positive critical events in the treatment, support and self categories, it was not possible to assess their effects, if any, on perceptions of ESRD and hemodialysis. The simplistic scoring of the critical events (i.e., yes/no) makes it difficult to interpret the findings (i.e., not all critical events are likely to be of equal importance to all subjects). Furthermore, assigning a single score (i.e., presence or absent) to the simultaneous occurrence of multiple positive and negative events limits the meaningfulness

and conclusiveness of the findings. The presentation of the findings is organized according to significant influencing factors (i.e., negative and positive illness, negative treatment, negative support, and negative self events). Table 9 presents a summary of study findings.

Positive and negative illness events. Participants who experienced positive illness events were significantly more likely to be satisfied with performance of ADL, $t(58) = -2.50$, $p = .02$, and to experience less psychosocial distress, $t(58) = -2.69$, $p = .009$, than their counterparts without such events. In contrast, participants who experienced negative illness events had significantly lower levels of emotional well-being, $t(50.37) = 2.20$, $p = .033$, and greater levels of psychosocial distress, $t(58) = 3.04$, $p = .004$, than those who did not have such events. Interestingly, participants who experienced negative illness events were also significantly more satisfied with family support, $t(58) = -2.08$, $p = .04$, than their counterparts without such events.

Negative treatment events. Participants who experienced negative treatment events were significantly more likely to report greater physiological stressors, $t(57) = 2.17$, $p = .04$, and were less likely to be satisfied with support from nurses, $t(58) = 2.31$, $p = .03$, and allied health professionals, $t(22.72) = 3.15$, $p = .005$, than their counterparts who did not experience these events.

Table 9

Independent t-tests for Perception of ESRD and Hemodialysis and Critical Events

Variables	PI	NI	NT	NS	NSF
Illness/Treatment Experiences					
Physiological Stressors	-0.71	1.19	2.17*	0.68	0.95
Performance of ADL	-2.50*	1.46	0.07	-1.48	2.28*
Knowledge	0.50	-0.73	-0.49	0.02	-0.45
Self-Health	-0.31	1.35	-0.51	0.13	-2.44*
Social Supports					
Family	0.55	-2.08*	0.69	2.25*	0.19
Nurses	-0.47	0.74	2.31*	0.78	0.69
Physicians	-0.68	1.49	1.69	1.26	0.66
Allied Health	-0.00	-0.61	3.15**	0.91	-0.59
Adjustment to a New Normal					
Emotional Well-Being	-1.40	2.20*	0.81	0.83	1.89
Psychosocial Distress	-2.69**	3.04**	2.03	-0.16	4.01***

Note. PI = Positive Illness Events. NI = Negative Illness Events. NT = Negative Treatment Events. NS = Negative Support Events. NSF = Negative Self Events. ADL = Activities of Daily Living.

* $p < .05$. ** $p < .01$. ***$p < .001$.

Negative support and self events. Only one significant difference was noted in participants' perceptions based on the occurrence of negative support events. Specifically, participants experiencing negative support events were less likely to be satisfied with support from their family, $t(52.78) = 2.25$, $p = .028$.

With regard to negative self events, participants who experienced such events were significantly less satisfied with their performance of ADL, $t(58) = 2.28$, $p = .026$, more likely to be involved in self-health management, $t(58) = -2.44$, $p = .018$, and more likely to experience increased psychosocial distress, $t(45.46) = 4.01$, $p = .000$.

HRQOL and Critical Events

Again with all of the participants reporting positive treatment, support and self events, it was also not possible to assess their affects on HRQOL. As well, there were no significant effects found for negative treatment and support events. The presentation of the findings is limited to the effect of negative and positive illness events, and negative self events on overall physical and mental health.

The findings indicated that participants who experienced positive illness events were more likely to have better overall physical health, $t(58) = -2.71$, $p = .009$, than those without such events. Similarly, participants who experienced negative illness events were significantly less likely to have good overall physical health, $t(58) = 2.40$, $p = .02$, than those without such events. Negative self

events were not found to significantly influence overall physical health.

With regards to overall mental health, participants who experienced negative illness events, $t(57.39) = 2.48$, $p = .016$, and negative self events, $t(44.07) = 3.65$, $p = .001$, were significantly more likely to have worse overall mental health. Positive illness events was not found to significantly influence overall mental health.

Experiences, Supports, and Adjustment

The discussion in this section is focused on how illness and treatment experiences and social supports relate to adjustment to a new normal at both baseline and follow-up. The findings are organized according to the major content domains of adjustment (i.e., emotional well-being and psychosocial distress). Table 10 provides a summary of the correlations for both time periods.

Emotional well-being. A few statistically, significant positive correlations were observed between emotional well-being and select experience and support variables at both time periods. Interestingly, there were notable inconsistencies between the time periods. At baseline, greater satisfaction with performance of ADL, greater confidence with illness and treatment knowledge, and greater satisfaction with family, nurse, and physician support were significantly correlated with greater emotional well-being. Based on the coefficient of determination (i.e., r^2), satisfaction with performance of ADL and confidence with knowledge about

illness and treatment accounted for 10.9% and 11.6%, respectively, of the variance in emotional well-being. As well, family, nurse, and physician support accounted for 8.4%, 18.5%, and 36%, respectively, of the explained variance. At follow-up, knowledge confidence and satisfaction with family and nursing support failed to achieve statistical significance with emotional well-being. As well, physiological stressors now became a significant correlate and satisfaction with performance of ADL and physician support continued to depict a significant relationship. Based on the coefficient of determination (i.e., r^2), less physiological stressors, greater satisfaction with performance of ADL, and greater physician support accounted for 7.8%, 21.2%, and 9%, respectively, of the explained variance in greater emotional well-being.

Psychosocial distress. A few statistically, significant positive correlations were also observed between psychosocial distress and select experience and support variables at both time periods. Similar to emotional well-being, inconsistencies occurred between the time periods.

At baseline, fewer physiological stressors, greater satisfaction with performance of ADL, greater satisfaction with support from nurses and physicians were significantly correlated with less psychosocial distress (see Table 10). Based on the coefficient of determination (i.e., r^2), physiological stressors, performance of ADL, nursing, and physician support accounted for 19.4%, 10.9%, 18.5%, and 12.3%, respectively, of the explained variance in psychosocial distress.

At follow-up, the significant relationships between psychosocial distress and physiological stressors and physician support disappeared. As well, family support now became a significant correlate, while performance of ADL and nursing support continued to depict significant relationships with psychosocial distress (see Table 10). Based on the coefficient of determination (i.e., r^2), greater satisfaction with performance of ADL, less family support, and greater nursing support accounted for 6.8%, 16%, and 21.2%, respectively, of the explained variance in psychosocial distress.

Perception of ESRD and Hemodialysis and HRQOL

With data collection restricted to the follow-up period for HRQOL, the presentation of findings is limited to the correlations observed between HRQOL and perceptions of ESRD and hemodialysis at the follow-up period only. The discussion is organized according to the major components of HRQOL (i.e., overall physical and mental health).

Physical health. The findings revealed few significant relationships between the PCS and illness and treatment, support, and adjustment variables at follow-up. Statistically, significant correlations were positive and in the low to moderate range. Less frequent physiological stressors, greater satisfaction with performance of ADL, and less psychosocial distress were significantly correlated

Table 10

Experiences and Supports with Adjustment at Baseline and Follow-up

Variable	Baseline *r*		Follow-up *r*	
	EWB	**PSD**	**EWB**	**PSD**
Illness/Treatment Experiences	.40**	.47**	.46***	.19
Physiological Stressors	.18	.44***	.28*	.24
Performance of ADL	.33**	.33**	.46**	.26*
Knowledge	.34**	.14	.18	.07
Self-Health Management	.15	-.00	.06	-.20
Social Supports	.56***	.36**	.27	.16
Family	.29*	-.03	.18	-.40**
Nurses	.43**	.43**	.19	.46***
Physicians	.60***	.35**	.30*	.11
Allied Health Professionals	.21	.07	.08	-.13

* $p < .05$. ** $p < .01$. *** $p < .001$.

Note. ADL = Activities of Daily Living. EWB = Emotional Well-Being. PSD = Psychosocial Distress.

with better physical health (see Table 11). Specifically, physiological stressors, performance of ADL, and psychosocial distress accounted for 7.8%, 12.3%, and 8.4%, respectively, of the variance in overall physical health.

Mental health. Although several significant positive relationships existed between the MCS and illness and treatment, support, and adjustment variables at follow-up, most pf the scores were in the low range. Specifically, less frequent physiological stressors, greater satisfaction with performance of ADL, less involvement in self- health management, greater physician support, greater emotional well-being, and less psychosocial distress were significantly correlated with improved mental health (see Table 11). Specifically, physiological stressors, performance of ADL, self-health management, physician support, emotional well-being, and psychosocial distress accounted for 13.7%, 10.9%, 6.8%, 9.6%, 29.2%, and 23%, respectively, of the explained variance in overall mental health.

Reliability and Validity of Study Instruments

The reliability and validity of the PPHS and the SF - 36 were also examined for the study population. Cronbach's alpha was used to assess internal consistency. The intercorrelations among subscales and total scores were used to assess construct validity.

Table 11

Perception of ESRD and Hemodialysis at Follow-up with PCS and MCS

Variable	PCS	MCS
Illness/Treatment Experiences	.34**	.30**
Physiological Stressors	.28*	.37**
Performance of ADL	.35**	.33**
Knowledge	-.10	.13
Self-Health Management	.11	-.26*
Social Supports	.15	.21
Family	.01	.03
Nurses	.16	.20
Physicians	.20	.31*
Allied Health Professionals	.11	-.19
Adjustment to New Normal	.34**	.62***
Emotional Well-Being	.25	.54***
Psychosocial Distress	.29*	.48***

Note. PCS = Physical Component Score. MCS = Mental Component Score.

*$p < .05$. **$p < .01$. ***$p < .001$.

PPHS

This section presents the psychometric findings on the PPHS. The discussion is organized according to relevant reliability and validity findings.

Reliability. Table 12 provides the alpha coefficients for the PPHS and its subscales at baseline and follow-up. The total PPHS had an alpha coefficient of .91 at baseline and .86 at follow-up, indicating a high level of internal consistency.

Alpha coefficients for the overall illness and treatment experience scale was .59 to .43 at baseline and follow-up, respectively, with subscale values ranging from .26 to .64. As well, alpha coefficients for the overall social support scale was .88 to .80 at baseline and follow-up, respectively, with subscale values ranged from .35 to .91. Finally, alpha coefficients for the overall adjustment scale was .89 at baseline and .86 at follow-up, with subscale values ranging from .81 to .86.

While the reliability values of the major scales (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) were fairly good at both baseline and follow-up, some of their subscales evidenced very low internal consistency. The most problematic were the performance of ADL and knowledge confidence of the illness and treatment experience subscale, and allied health of the social support scale. One plausible explanation for these low internal consistencies was the small number of items comprising these

Table 12

Alpha Coefficients of PPHS at Baseline and Follow-up

Variable	PPHS Baseline ∝	PPHS Follow-up ∝
Illness/Treatment Experiences	.59	.43
Physiological Stressors	.64	.52
Performance of ADL	.36	.54
Knowledge	.56	.26
Self-Health Management	.55	.52
Social Supports	.88	.80
Family	.50	.63
Nurses	.85	.80
Physicians	.91	.86
Allied Health Professionals	.46	.35
Adjustment to a New Normal	.89	.86
Emotional Well-Being	.81	.82
Psychosocial Distress	.86	.86
Patients' Perceptions of Hemodialysis Scale	.91	.86

scales. The small sample size could also be a contributing factor. Finally, the low reliability scores of some of the subscales also suggest that more work is needed to fine tune ambiguously worded items.

Validity. A preliminary step in assessing the construct validity of an instrument is to examine the correlations of subscales with total instrument scores, as well as the intercorrelations among major subscales (i.e., illness and treatment experiences, social supports, and adjustment to a new normal). All of the major subscales demonstrated moderate to strong, positive correlations with the total PPHS score at both baseline and follow-up (see Tables 13 and 14). However, some noteworthy differences were observed. While moderate, significant correlations existed among the major subscales at baseline, only illness and treatment experiences correlated significantly with overall adjustment at follow-up. In addition, the individual subscales comprising illness and treatment experiences, social supports, and overall adjustment depicted moderate to strong correlations with relevant total scores at both baseline and follow-up. For example, physiological stressors, confidence with knowledge, performance of ADL, and self-health management were more strongly correlated with the overall experience scores than either the overall social support or adjustment scores.

Table 13

Correlations among PPHS at Baseline

Variable	2	3	4	5	6	7	8	9	10	11	12	13	PPHS
1. OIT	.77†	.55†	.52†	.28*	.44‡	.20	.38‡	.38‡	.38‡	.50†	.40‡	.47†	.74†
2. PS		.20	.09	-.00	.26	.15	.18	.27*	.26	.38‡	.18	.44†	.53†
3. ADL			.21	-.05	.29*	.02	.34‡	.29*	.17	.37‡	.33‡	.33‡	.47†
4. KL				-.02	.30*	.06	.30*	.22	.29*	.25	.34‡	.14	.39‡
5. SHM					.20	.40‡	.09	.07	.22	.07	.15	-.00	.15
6. OSS						.52†	.83†	.82†	.62†	.50†	.56†	.36‡	.77†
7. FA							.19	.23	.39‡	.12	.29*	-.03	.26
8. RN								.58†	.37‡	.49†	.43‡	.43‡	.68†
9. MD									.36‡	.51†	.60†	.35‡	.69†
10. AH										.15	.21	.07	.40‡
11. OADJ											.83†	.92†	.90†
12. EW												.55†	.78†
13. PSD													.82†

Note. OIT = Overall Illness and Treatment Experiences. PS = Physiological Stressors. ADL = Activities of Daily Living. KL = Knowledge. SHM = Self-Health Management. OSS = Overall Supports. FA = Family Support. RN = Nursing Support. MD = Physician Support. AH = Allied Health Professionals. OADJ = Overall Adjustment to a New Normal. EW = Emotional Well-Being. PSD = Psychosocial Distress. PPHS = Patient Perceptions of Hemodialysis Scale. * = $p < .05$. ‡ = $p < .01$. † = $p < .001$.

Table 14

Correlations among PPHS at Follow-up

Variable	2	3	4	5	6	7	8	9	10	11	12	13	PPHS
1. OIT	.66†	.37‡	.50†	.45†	.22	.10	.14	.09	.27	.36‡	.46†	.19	.63†
2. PS		.01	.13	-.14	.19	-.03	.25	.09	.21	.31‡	.28*	.24	.46 ‡
3. ADL			-.07	.03	.06	.10	.03	.10	-.05	.41‡	.46†	.26*	.44‡
4. KL				.09	.17	-.05	.15	-.03	.18	.10	.18	.07	.35‡
5. SHM					.04	.21	-.19	.00	.16	-.09	.06	-.20	.13
6. OSS						.47†	.70†	.78†	.39‡	.25	.27	.16	.59†
7. FAM							-.05	.21	.23	-.19	.18	-.40‡	.08
8. RN								.40‡	-.01	.42‡	.19	.46†	.54†
9. MD									.15	.28*	.30‡	.11	.49†
10. AHP										-.06	.08	-.13	.24
11. OADJ											.73†	.88†	.88†
12. EW												.32*	.75†
13. PSD													.70†

Note. OIT = Overall Illness and Treatment Experiences. PS = Physiological Stressors. AD = Activities of Daily Living. KL = Knowledge. SHM = Self-Health Management. OSS = Overall Supports. FA = Family Support. RN = Nursing Support. MD = Physician Support. AHP = Allied Health Professionals. OADJ = Overall Adjustment to a New Normal. EW = Emotional Well-Being. PSD = Psychosocial Distress. PPHS = Patient Perceptions of Hemodialysis Scale. * = $p < .05$. ‡ = $p < .01$. † = $p < .001$.

In summary, there is some evidence suggesting that all of the major subscales are measuring some aspect of the same construct. Although less conclusive, there is some support for the interrelations among the major subscales, as well as minor with major subscales. These findings suggest that both minor and major subscales are measuring some distinct aspect of individuals perceptions of ESRD and hemodialysis. Overall, study findings suggest that the PPHS has good construct validity.

Short Form - 36

This section summarizes the psychometric findings on the SF - 36. The discussion is organized according to relevant reliability and validity findings.

Reliability. Alpha coefficients were calculated for the PCS and the MCS, and their relevant subscales. Alpha values for the PCS and MCS were .82 and .88, respectively (see Table 15). As well, alpha values ranged from .70 to .92 and .82 to .88 for the PCS and MCS subscales, respectively. These findings indicate that the SF - 36 evidenced excellent internal consistency.

Validity. Interestingly, the physical component score and the mental component score failed to significantly correlate with each other. However, subscale scores demonstrated moderate to strong, positive correlations with the

Table 15

Alpha Coefficients of SF - 36

Variable	∝
Physical Component Score (PCS)	.82
Physiological Functioning	.88
Role Functioning Physical	.84
Bodily Pain	.92
General Health	.70
Mental Component Score (MCS)	.88
Vitality	.82
Social Functioning	.88
Role Functioning Emotional	.85
Mental Health	.83

relevant PCS or MCS score (see Table 16). In all instances, minor subscales depicted stronger correlations with the relevant major score than its counterpart. These findings suggest that all of the relevant subscales are measuring some aspect of physical or mental health.

Summary

Study participants were generally positive about illness and treatment experience, social supports, and adjustment to a new normal at both baseline and follow-up. The only significant changes observed over time were the decreased satisfaction with family supports and decreased involvement in self-health management activities. Demographic variables and medical risk factors exerted minimal, and sometimes inconsistent, effects on most experience, support, and adjustment variables. Increased age was correlated with greater knowledge confidence and less psychosocial distress at both time periods. Living with a spouse was significantly associated with fewer physiological stressors and greater satisfaction with family supports at follow-up, but not at baseline. A greater length of time on hemodialysis was correlated with decreased satisfaction with nursing support and greater psychosocial distress at follow-up, but not at baseline. While greater illness severity was associated with less knowledge confidence at both time periods, greater illness severity only correlated with greater psychosocial distress at baseline. In addition, greater

Table 16

Correlations Between SF - 36 Summary Scores and Subscales

Variable	Physical Component Score	Mental Component Score
Physical Functioning	.70***	.13
Role Functioning Physical	.64***	.47***
Bodily Pain	.76***	.33**
General Health	.39**	.35**
Vitality	.53***	.56***
Social Functioning	.57***	.75***
Role Functioning Emotional	.14	.76***
Mental Health	.16	.85***

*$p < .05$. **$p < .01$. *** $p < .001$.

illness severity and more co-morbid illnesses were associated with more frequent physiological stressors at follow-up, but not at baseline. Increased urea reduction rate was associated with better emotional well-being at baseline, but not at follow-up. Finally, increased phosphorus was correlated with decreased satisfaction with performance of ADL and decreased satisfaction with AHP at baseline, but not at follow-up.

Study findings indicated that critical events that occurred between baseline and follow-up exerted minimal effects on individuals' perceptions of ESRD and hemodialysis at follow-up. Positive illness events were significantly correlated with less satisfaction with performance of ADL and less psychosocial distress. The occurrence of negative illness events were significantly associated with greater satisfaction with support from family, lower emotional well-being, and increased psychosocial distress. Negative treatment events demonstrated a significant relationship with increased frequency of physiological stressors and less satisfaction with support from nurses and allied health. Negative support events were associated with less satisfaction with support from family. Finally, negative self events were significantly correlated with less satisfaction with performance of ADL, more involvement in self-health management, and increased psychosocial distress.

A few of the illness and treatment and support variables at baseline and follow-up were found to exert a significant, positive influence on adjustment

variables (i.e., emotional well-being and psychosocial distress) at both time periods, however, the findings were inconsistent over time. Increased physiological stressors were correlated with decreased emotional well-being at follow-up, but not at baseline. Greater confidence in knowledge and greater satisfaction with support from family and nurses were significantly correlated with increased emotional well-being at baseline, but not at follow-up. Greater satisfaction with performance of ADL and greater support from physicians were significantly correlated with emotional well-being at both time periods.

Less frequency of physiological stressors and greater satisfaction with physician support were significantly related to less psychosocial distress at baseline, but not at follow-up. Greater satisfaction with support from family was significantly associated with greater psychosocial distress at follow-up, but not at baseline. Greater satisfaction with performance of ADL and support from nurses, and greater emotional well-being were significantly associated with less psychosocial distress at both baseline and follow-up.

The study findings indicated that participants experienced excellent overall mental health. In contrast, most participants experienced substantial limitations in overall physical health. None of the demographic variables or medical risk factors were found to influence overall mental health. While none of the demographic variables were found to influence overall physical health, a few medical risk factors exerted minimal effects. More co-morbid illnesses, longer

time on hemodialysis, and lower albumin were significantly correlated with worse physical health.

Critical events demonstrated minimal effects on overall physical and mental health. While positive illness events were significantly related to better physical health, negative illness events were associated with poorer physical health. Negative illness and negative self events were significantly correlated with worse overall mental health.

Select experience, support, and adjustment variables were found to exert a significant effect on overall physical and mental health, with the greatest influence being on overall mental health. Fewer physiological stressors, greater satisfaction with performance of ADL, and less psychosocial distress were significantly associated with better overall physical health. Finally, fewer physiological stressors, greater satisfaction with performance of ADL, decreased involvement in self-health management, greater satisfaction with support from physicians, greater emotional well-being, and less psychosocial distress were associated with better overall mental health.

CHAPTER 5

Discussion

The LESRD-H model was used as the framework for the current study. The discussion of findings is organized according to the major components of the model: perceptions of ESRD and hemodialysis (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) and quality outcome (i.e., overall physical and mental health). Consideration is also given to select factors affecting intermediate outcome or adjustment (i.e., psychosocial distress and emotional well-being) and overall physical and mental health.

The LESRD-H model proposes that illness and treatment experiences and social supports exert a direct effect on intermediate outcomes. As well, illness and treatment experiences, social supports, and adjustment are postulated to exert direct and indirect effects on quality outcomes. The focus of the current study is restricted to the direct effects of study variables on quality outcome.

Perception of ESRD and Hemodialysis

The current study investigated changes in individuals' perception of illness and treatment experiences, satisfaction with social supports, and adjustment to a new normal from study initiation to approximately seven months later. The discussion is organized according to these constructs.

Illness and Treatment Experiences

The aspects of illness and treatment experiences investigated in the current study included the frequency of physiological stressors (e.g., fatigue, dyspnea, muscle cramps, pruritus, etc.), confidence with illness and treatment knowledge (i.e., benefits and side effects of hemodialysis, food and fluid restrictions, cause of illness, and kidney transplant requirements), satisfaction with performance of ADL (i.e., ability to work and do household chores, assume responsibility for self-care, and participate in social activities), and level of involvement in self-health management (i.e., adhering to food and fluid restrictions, monitoring nurses activities, and monitoring for and reporting problems to nurses). The overall mean scores for the illness and treatment experience scale indicate that most participants were sometimes bothered by physiological stressors, moderately satisfied with performance of ADL, moderately confident with illness and treatment knowledge, and often involved in self-health management at both baseline and follow-up.

Similar to the current study's findings, Baldree et al. (1982) and Killingworth and Van Den Akker (1996) documented moderate levels of physiological stressors in hemodialysis patients. Counter to the current study's findings, several researchers (Bihl et al., 1988; Fuchs & Schreiber, 1998; Gurklis & Menke, 1988; Klang & Clyne, 1997; Lev & Owen, 1998; Parfrey et al., 1988; Parfrey et al., 1989; Welch & Austin, 1999) found that hemodialysis patients

experienced mild physiological stressors. The most problematic physiological stressors at baseline and follow-up were feelings of fatigue and low energy levels, and feelings of exhaustion after hemodialysis. Several researchers (Baldree et al.; Bihl et al.; Cormier-Daigle & Stewart, 1997; Curtin et al., 2002; Faber, 2000; Gregory et al., 1998; Gurklis & Menke, 1988, 1995; Killingworth & Van Den Akker, 1996; Klang & Clyne; Lok, 1996; Parfrey et al., 1988; Welch & Austin) have identified fatigue and/or exhaustion as sources of stress for hemodialysis patients.

No comparable quantitative studies were reviewed that examined satisfaction with performance of ADL, or confidence with illness and treatment knowledge in the hemodialysis population. However, several qualitative studies have documented the importance of assuming independence with self-care activities (Gurklis & Menke, 1995; Jones & Preuett, 1986; Kutner, 1987; Nagle, 1998) and being knowledgeable about the illness and treatment (Gregory et al.,1998; Gurklis & Menke; Kutner; Nagle).

Active participation in self-health management is also viewed as a defining factor for illness and treatment experiences. Only one quantitative study was identified that examined self-health management. Lev and Owen (1998) reported that participants were confident with the use of self-care self efficacy strategies (i.e., coping, stress reduction, making decisions, and enjoying life) that could improve their health. As well, several qualitative studies have found that

individuals on hemodialysis tend to follow recommended treatment plans, and assume a great deal of responsibility for monitoring their health and the activities of health care providers (Gregory et al., 1998; Gurklis & Menke, 1995; Jones & Preuett, 1986; Nagle, 1998).

One of the research questions investigated in the current study focused on the stability of illness and treatment experiences over an average of seven months. While most indicators (i.e., physiological stressors, performance of ADL, and confidence with knowledge) were stable over time, there was evidence of a significant decline in self-health management at follow-up. Similar to the current study's findings Klang and Clyne (1997) reported no change in physiological stressor levels over time. In contrast, Lev and Owen (1998), Welch and Austin (1999), and Parfrey et al. (1989) reported a slight improvement in stressor levels. No quantitative studies were reviewed that examined changes in satisfaction with performance of ADL, and confidence with knowledge. Only one quantitative study was identified on self-health management. Lev and Owen reported inconsistent changes in hemodialysis patients confidence with self-care practices. One explanation for the current study's findings on self-health management may be a function of ambivalence toward the treatment regime (i.e., dichotomy between knowing versus doing). Gregory et al. (1998) reported that study participants experienced a great deal of ambivalence between knowing what should be done and actually doing.

Social Support

In the current study, consideration was given to participants levels of satisfaction with formal (i.e., nurses, physicians, and allied health professionals) and informal (i.e., family) support systems. The mean scores for the total social support scale indicated that participants were very satisfied with their overall supports. Other researchers have also reported that hemodialysis patients tend to give moderate to strong ratings to their overall social support networks (Gregory et al., 1998; Gurklis & Menke, 1995; Kimmel et al., 1996; Kimmel et al.,1998; Kimmel et al., 2000; Kovac, et al., 2002; Kutner, 1987; Patel et al., 2002).

In the current study, participants were more satisfied with support from health care providers than family members at both time periods. These findings conflict with those of other researchers who reported that individuals on hemodialysis tend to give higher ratings to family than health care provider support (Cormier-Daigle & Stewart, 1997; Gregory et al.; Gurklis & Menke, 1995; Kutner; Siegal et al., 1997; Weil, 2000). While the reason for the conflicting findings is unclear, the reliance on a 3-item scale to assess family support and the resulting low to moderate internal consistency in the current study may be a contributing factor.

In the current study, participants were quite satisfied with family supports at both time periods. Comparable findings have been reported by other

researchers (Christensen et al., 1992; Gregory et al., 1998; Gurklis & Menke, 1995; Kutner, 1987; Weil, 2000; White & Grenyer, 1999). Kimmel et al. (1996) and Kimmel et al. (2000) also found that individuals on hemodialysis were satisfied with dyadic relationships. In the current study, participants made an effort to try to lessen the impact of the illness and treatment on family members. Gregory et al. and White and Grenyer also speak to the reciprocal relationships within families.

In the current study, participants were very satisfied with the informational, tangible, and emotional support provided by health care providers at both baseline and follow-up. Similar findings have been reported by other researchers (Ferrans et al.1987; Gregory et al., 1998; Gurklis & Menke, 1995; Kutner, 1987; Siegal et al., 1987; Kovac et al., 2002).

Another focus of the current study was to document any changes in participant ratings of social supports between baseline and 7-months follow-up. In the current study, satisfaction with overall supports remained stable over time. Kimmel et al. (1998) also found that overall support scores were relatively stable over a one year period. In the current study, while satisfaction with formal support systems remained stable over time, satisfaction with family supports decreased significantly at follow-up. No comparable studies were found that specifically examined changes in family, nursing, physician, or allied health support over time. However, Kimmel et al. (2000) reported that satisfaction with

dyadic relationships remained stable over a one year time period. One plausible explanation for the decline in satisfaction with informal supports could be normal changes in family dynamics. For example, Kutner (1987) noted that family members are both sources of support and strain (i.e., due to undercaring and overcaring behaviors). Cormier-Daigle (1997) also found that individuals on hemodialysis not only receive high levels of support from families but also experience high levels of conflict.

Adjustment to a New Normal

In the current study, adjustment to a new normal was assessed in terms of emotional well-being and psychosocial distress. While individuals on hemodialysis may be adjusting fairly well emotionally, they also experience variant levels of psychosocial distress from time to time.

The current study's findings indicate that most individuals had high levels of emotional well-being (i.e., accepted dialysis and coping well) at both time periods. Similarly, there is some support from quantitative (Keogh & Feehally, 1999) and qualitative (Gregory et al., 1998; Nagle, 1998; O'Brien, 1983; Rittman et al., 1993) study findings that individuals on hemodialysis experience moderate to strong acceptance of and adjustment to illness and treatment requirements. From a somewhat similar perspective, some researchers (Baldree et al., 1988; Cormier-Daigle & Stewart, 1997; Faber, 2000; Gregory et al.,1998; Gurklis &

Menke, 1988, 1995; Kutner, 1987; Lok, 1996; Nagle; Rittman et al.) have found evidence for a key role played by effective coping strategies in facilitating successful adjustment.

In the current study, most individuals were experiencing a low to moderate degree of psychosocial distress at both time periods. Similarly, there is some evidence suggesting that individuals on hemodialysis experience mild distress levels (e.g., depression and anxiety, etc.) and minor adjustment problems (e.g., role disruptions, vocational, sexual, adjustment, etc.) (Kimmel et al., 1995; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Klang & Clyne, 1997; Kovac et al., 2002; Lev & Owen, 1998; Patel et al., 2002; Sacks et al., 1990). Other researchers (Killingworth & Van Den Akker,1996; Seigal et al., 1987; Walters et al., 2002) have documented the presence of clinical depression in the hemodialysis population.

In the current study, there were no significant changes in participants' levels of emotional well-being and psychosocial distress between baseline and follow-up. Similarly, Parfrey, et al. (1989) found that affect and well-being remained unchanged over a one year period in a stable group of hemodialysis patients. As well, anxiety and depression levels tend to remain relatively stable over short periods of time in the hemodialysis population (Kimmel et al., 1998; Klang & Clyne, 1997; Lev & Owen, 1998).

Quality Outcome

In the current study, HRQOL was investigated in terms of overall physical and mental health at follow-up. The aspects of physical health investigated in the current study included physical functioning, role functioning limitations due to physical health, perceived general health, and bodily pain. Aspects of mental health examined included general mental health, role functioning limitations due to emotional health, social functioning, and vitality. The most problematic areas of functioning were perceived general health, vitality, physical functioning, and role functioning physical. Similar findings were documented in other studies of hemodialysis patients (DeOreo, 1997; Diaz-Buxo et al., 2000; Kutner et al.; Manns et al., 2002; Merkus et al., 1997; Meyer et al., 1994; Walters et al., 2002).

Physical health. In the current study, participants were experiencing substantial limitations in their overall physical health, with overall scores below population norms. Similar findings have been reported by other researchers (Curtin et al., 2002; DeOreo, 1997; Diaz-Buxo et al., 2000; Kutner et al., 2000; Walters et al., 2002). Other instruments (e.g., KS, SQLI, SIP, etc.) besides the SF - 36 have also been used to assess select aspects of physical health. Similar to the current study's findings, Lok (1996) found that individuals on hemodialysis had moderate impairments in physical functioning. In contrast, other study findings suggest that hemodialysis patients experience mild limitations in objective and subjective physical functioning (Killingworth & Van Den Akker,

1996; Kimmel et al., 1995; Kimmel et al.,1996; Klang & Clyne, 1997; Kovac et al., 2002; Lev & Owen, 1998; Parfrey et al., 1989; Patel et al., 2002; Tell et al., 1995).

Mental health. The current study's findings indicate that participants were experiencing excellent mental health, with an overall score slightly above population norms. Other researchers (Curtin et al., 2002; DeOreo, 1997; Diaz-Buxo et al., 2000; Kutner et al., 2000; Walters et al., 2002) have also reported that hemodialysis patients experience excellent mental health, with scores relatively similar to healthy populations. As with physical health, additional instruments (e.g., SQLI, SIP, CIWB, etc.) have been used to assess mental health. While there is some empirical evidence suggesting that hemodialysis patients have very good mental functioning (Klang & Clyne, 1997; Parfrey et al., 1989), significant mental health concerns have also been documented in this population (Lok, 1996; Manns et al., 2002; Walters et al.).

Factors Influencing Adjustment and HRQOL

Another focus of the current study was to examine the effects of different factor groupings (i.e., illness and treatment experiences, social supports, critical events, demographics, and medical risk factors) on indicators of adjustment. As well, consideration was given to the effects of these same factor groupings plus the adjustment indicators on quality outcome. The discussion is organized

according to outcome variables (i.e., adjustment to a new normal and HRQOL).

Adjustment to a New Normal

One of the research questions in the current study examined the effects of illness and treatment experiences and social supports on adjustment to a new normal. Other questions focused on the influence of demographics (i.e., age, gender, and living arrangements), medical risk factors (i.e., time on hemodialysis, phosphorus, hemoglobin, albumin, urea reduction rate, illness severity, number of co-morbid illnesses, and hospitalizations between the study periods), and critical events. The discussion is organized around the two aspects of adjustment (i.e., emotional well-being and psychosocial distress) explored in the current study.

Emotional well-being. In the current study, select aspects of the illness and treatment experience were found to correlate with emotional well-being. While greater satisfaction with performance of ADL significantly correlated with greater emotional well-being at both time periods, inconsistencies were observed with other factors (i.e., greater knowledge confidence at baseline only, and fewer physiological stressors at follow-up only). Self-health management did not exert a significant effect at either time period.

While no comparable longitudinal studies were identified from the literature, several cross-sectional and qualitative studies examined the influence

of illness and treatment experiences on emotional well-being. Similar to the current study, qualitative findings provide support for the link between greater participation in ADL and greater overall well-being and illness acceptance (Gregory et al., 1998; Gurklis & Menke, 1995; Nagle, 1998; Weil, 2000). There is also some empirical support for the significant influence of fewer physiological stressors (Barrett et al., 1990; Devins et al., 1997) and greater understanding about the illness and treatment (Faber, 2000; Gregory et al.; Gurklis & Menke; Kutner, 1987; Nagle; Rittman et al., 1993) on greater emotional well-being. In contrast to the current study's findings, the importance of self-health management for achieving a greater sense of normalcy and overall well-being has been documented in the qualitative literature (Faber; Gregory et al; Jones & Preuett, 1986; Nagle; Rittman et al.).

In the current study, greater emotional well-being was significantly correlated with greater satisfaction with overall social supports at baseline only. While greater satisfaction with physician support correlated with greater emotional well-being at both time periods, greater satisfaction with family and nurses support were only significant correlates at baseline. Support from allied health professionals failed to correlate with emotional well-being at either time period. While no comparable studies were identified from the literature reviewed, there is some evidence from qualitative studies suggesting that the support received from informal and formal networks plays an important role in

facilitating adjustment (Kutner, 1987; Nagle, 1998; Weil, 1999).

In the current study, critical events exerted minimal effects on emotional well-being, with the presence of negative illness events significantly related to lower levels of emotional well-being. While no comparable studies were found in the literature, some evidence supports the effects of illness intrusiveness on emotional well-being. Devins et al. (1997) found that younger adults with higher levels of perceived illness intrusiveness had lower levels of psychosocial well-being when they viewed themselves as dissimilar to individuals with chronic kidney disease.

In the current study, none of the demographic variables were associated with emotional well-being at either baseline or follow-up. Although no comparable longitudinal studies were identified from the literature reviewed, cross-sectional studies evidenced similar and contrasting findings. In contrast to the current study's findings, Devins et al. (1997) found that increased age was predictive of greater psychosocial well-being. With coping an important component of emotional well-being in the current study, comparison was also made to studies examining the association between demographic variables and coping strategies. Similar to the current study, Baldree et al. (1982) and Cormier-Daigle (1997) found no significant association between age and type of coping strategies. In contrast, Blake and Courts (1996) found that older individuals used more affective coping strategies than their younger

counterparts. Conflicting findings were also reported for gender. While Baldree et al. failed to document a significant effect, Blake and Courts found that females used more problem-oriented coping strategies than males.

In the current study, medical risk factors exerted minimal effects on emotional well-being at both time periods. Greater urea reduction rate correlated with greater emotional well-being at baseline only. Similar to the current study's findings, time on dialysis was not found to influence use of coping strategies (Baldree et al.; Lok, 1996), or illness acceptance (Keogh & Feehally, 1999). Counter to the current study's findings, Gurklis and Menke (1988) found that greater time on dialysis correlated with greater use of problem-oriented coping, while Devins et al. found that less frequent co-morbid illnesses correlated with increased well-being.

Psychosocial distress. In the current study, illness and treatment experiences had minimal effects on psychosocial distress. Only greater satisfaction with performance of ADL significantly correlated with less distress at both time periods. While conflicting findings were observed for stressors (i.e., fewer physiological stressors with less distress at baseline), knowledge confidence and self-health management failed to achieve statistical significance at either time period. Although no comparable longitudinal studies were identified from the literature review, a few cross-sectional quantitative, as well as qualitative, studies provide parallel support for the effects of illness and treatment

experiences on distress levels. Similar to the current study's findings, Killingworth and Van Den Akker (1996) found that greater physiological stressors were correlated with greater anxiety, depression, and overall psychosocial maladjustment. As well, Devins et al. (1997) found that greater uremic symptoms and greater illness intrusiveness were related to greater distress.

In the current study, greater satisfaction with overall supports was significantly correlated with less psychosocial distress at baseline only. Again no longitudinal studies were identified that specifically examined correlations between levels of support and distress over time. However, a few cross-sectional studies provide somewhat comparable results. Similar to the current study's findings, greater satisfaction with overall supports has been correlated with lower depression levels (Kimmel et al., 1995; Kimmel et al.,1996; Kimmel et al., 2000), greater social adjustment (Kimmel et al., 1995; Kimmel et al., 1996), and greater vocational adjustment (Kimmel et al., 1995).

In the current study, greater satisfaction with nursing support significantly correlated with less psychosocial distress at both time periods. However, inconsistent findings were observed for physician and family support (i.e., less distress with greater satisfaction with physicians at baseline only; and greater satisfaction with family with greater distress at follow-up only). Satisfaction with support from allied health professionals failed to correlate with psychosocial distress at either time period. Only a couple of studies were identified that

examined the separate effects of formal and informal supports on distress levels. While Siegal et al. (1987) found that the helpfulness of the health care team depicted a low, but insignificant, association with psychological adjustment, greater support from family and friends was significantly related to greater psychological adjustment. As well, Kovac et al. (2002) failed to find a link between satisfaction with physicians and nurses and overall cognitive depression. In additional, greater satisfaction with marital and partner relationships significantly correlated with less depression (Kimmel et al., 1995; Kimmel et al.,1996; Kimmel et al., 2000), greater family and sexual relations adjustment (Kimmel et al., 1995; Kimmel et al.,1996) and greater social adjustment (Kimmel et al., 1996). The reason for the relationship between greater family support and greater distress at follow-up in the current study is unclear, however, some researchers have found that family relations can be both supportive and conflictual (Cormier-Daigle et al., 1997; Kutner, 1987).

In the current study, critical events correlated minimally with psychosocial distress. While the presence of positive illness events significantly correlated with less psychosocial distress, negative illness and self events were significantly related to greater psychosocial distress. While no comparable studies were identified from the literature, there is some support for the influence of positive and negative events or illness effects on distress. In a qualitative study, Gregory et al. (1998) found that individuals on hemodialysis who experience frequent

illness episodes and negative treatment events (e.g., access problems, machine malfunctions, etc.) tend to have greater psychological and emotional difficulties than those who rarely experience such events. Devins et al. (1997) found that increased stressful life illness events was related to greater emotional distress. Greater illness intrusiveness in various life domains has been correlated with greater depression (Kimmel et al., 1995; Kimmel et al.,1996; Kimmel et al.,1998; Sacks et al., 1990), greater role disruptions (Sacks et al.) and greater maladjustment (Kimmel et al., 1995; Kimmel et al., 1996).

In the current study, demographic variables exerted minimal influence on psychosocial distress at both baseline and follow-up. Greater age was significantly related to less psychosocial distress at both time periods. No comparable longitudinal studies were identified from the literature review. However, there is limited, albeit sometimes inconsistent, support for the influence of demographics on select aspects of distress (e.g., depression, role disruptions, social adjustment, etc.). Similar to the current study's findings, greater age was related to less emotional distress when individuals perceived themselves as similar to the chronic kidney patient (Devins et al., 1997). Age failed to correlate with depression (Killingworth & Van Den Akker, 1996; Kimmel et al., 1998; Klang & Clyne, 1997; Patel, et al., 2002; Walters et al., 2002), or psychological adjustment (Seigal et al., 1987). In contrast, greater age has been found to correlate with increased depression levels (Sacks et al., 1990), increased family

and sexual maladjustment (Kimmel et al., 1995), and greater role disruptions (Sacks et al., 1990). Similar to the current study's findings, gender was not found to correlate with depression (Killingworth & Van Den Akker; Kovac et al., 2000; Walters et al.), emotional distress (Devins et al.), anxiety (Killingworth & Van Den Akker), role disruptions (Sacks et al.), or psychological adjustment (Seigal et al.). In contrast, Kimmel et al. (2000) found that females had greater overall depression levels than males. As well, while Sacks et al. found that females had higher levels of cognitive depression, Patel et al. found that men had higher levels.

In the current study, medical risk factors exerted minimal effects on psychosocial distress at both baseline and follow-up. While greater time on hemodialysis significantly correlated with greater psychosocial distress at both time periods, increased illness severity significantly correlated with less psychosocial distress at baseline only. Similar to the current study's findings, Seigal et al. (1987) found that shorter time on dialysis was significantly related to greater psychological adjustment. In contrast, time on dialysis was not found to correlate with either depression (Killingworth & Van Den Akker, 1996) or role disruptions (Sacks et al.). Counter to the current study's findings, increased illness severity has been associated with greater overall depression and greater role disruptions (Sacks et al., 1990), and greater family and sexual maladjustment (Kimmel et al., 1995). In contrast, illness severity failed to

correlate with depression (Kimmel et al., 1995; Kimmel et al., 1996; Walters et al., 2002) or family and sexual adjustment (Kimmel et al., 1996). Similar to the findings in the current study, no relationship was found between depression and dialysis adequacy and albumin (Kimmel et al., 1998) or hemoglobin (Walters et al.). In addition, Kimmel et al. (1995) and Kimmel et al. (1996) failed to document any relationship between phosphorus and social, vocational, and family and sexual adjustment. While greater phosphorus significantly correlated with greater cognitive depression in a prevalent hemodialysis group (Kimmel et al., 1995), this relationship did not hold for a incident group (Kimmel et al., 1996).

HRQOL

One of the research questions in the current study investigated the effects of illness and treatment experiences, social supports, and adjustment to a new normal on overall physical and mental health. Additional questions considered the effects of demographics (i.e., age, gender, and living arrangements), medical risk factors (i.e., time on hemodialysis, phosphorus, hemoglobin, albumin, urea reduction rate, illness severity, number of co-morbid illnesses, and hospitalizations between the study periods), and critical events. The discussion is restricted to the effects of the above factors on overall physical health and mental health at follow-up only.

Physical health. In the current study, fewer physiological stressors and

greater satisfaction with performance of ADL significantly correlated with better overall physical health. Confidence with knowledge and self-health management failed to achieve statistical significance. Only two studies were identified from the literature that investigated the influence of illness and treatment experiences on overall physical health. Similar to the findings in the current study, better overall physical health has been associated with fewer physiological stressors (Curtin et al., 2002) and greater physical activity (Kutner et al., 2000). Other researchers have used different operational measures than the SF - 36 to assess physical health status (e.g., objective functional status, subjective behavioral functioning, etc.). Similar to the current study's findings, Barrett et al., (1990) and Lok (1996) found that fewer physiological stressors were related to improved functioning and well-being.

In the current study, none of the support variables were found to influence overall physical health. No studies were reviewed that examined the influence of social support on overall physical health as measured by the SF - 36. Similar to the current study's findings, Patel et al. (2002) failed to document any association between overall support and objective levels of physical functioning. As well, Kimmel et al. (1996) failed to document a significant effect for overall support and satisfaction with dyadic relationships on physical functioning in either incident or prevalent groups. In contrast, Tell et al. (1995) reported that greater overall support was correlated with greater subjective and objective physical

functioning.

In the current study, while less psychosocial distress was significantly correlated with better physical health, emotional well-being failed to achieve statistical significance. Only a few comparable studies were identified from the literature reviewed. Similar to the current study's findings, positive depression scores have been linked with greater limitations in overall physical health (Walters et al., 2002). As well, increased overall depression has been associated with greater difficulties with ADL (Killingworth & Van Den Akker (1996) and greater limitations in objective physical functioning (Patel et al., 2002). In addition, greater social maladjustment (Kimmel et al., 1995) and greater vocational maladjustment (Kimmel et al., 1996) have been significantly associated with greater limitations in objective physical functioning. In contrast to the current study's findings, Kimmel et al. (1995) and Kimmel et al. (1996) failed to document a significant link between overall depression and objective physical functioning.

In the current study, while a greater number of negative illness events was significantly correlated with poorer overall physical health, positive illness events were associated with better overall physical health. No comparable studies were found that examined the effects of critical events on overall physical health. However, counter to the current study's findings, Kimmel et al. (1995) and Kimmel et al. (1996) failed to document a significant correlation between

perceived illness intrusiveness and objective physical functioning.

In the current study, none of the demographic variables were found to influence physical health. Similar to the current study's findings, neither age (Klang & Clyne, 1997), gender (Klang & Clyne,1997; Patel et al., 2002; Tell et al., 1995), nor living arrangements (Tell et al.) were found to correlate with subjective and objective physical functioning. In contrast to the current study's findings, older age has been found to significantly correlate with poorer overall physical health (Curtin et al., 2002; Diaz-Buxo et al., 2000; Kutner et al., 2000; Walters et al., 2002) and increased limitations in objective and subjective physical functioning (Kimmel et al., 1995; Patel et al.; Tell et al.). As well, Walters et al. and Kutner et al. found that females were significantly more likely to have poorer overall physical health than men.

In the current study, several medical risk factors influenced overall physical health. Hospital admission during the study period, greater number of co-morbid illnesses, longer time on hemodialysis, and lower albumin levels were significantly associated with poorer physical health. Similar to the current study's findings, DeOreo (1997) found that a greater probability of hospitalization was associated with poorer overall physical health. As well, Kutner et al. (2000), failed to find a significant relationship between urea reduction rate and albumin and overall physical health. In addition, neither hemoglobin (Tell et al.) nor phosphorus (Kimmel et al.,1995; Kimmel et al.,1996) has been associated with

better physical health. Counter to the current study's findings, greater hematocrit (Kutner et al.) has been associated with greater overall physical health, and greater illness severity (Kimmel et al., 1995; Kimmel et al., 1996) has been associated with increased limitations in physical functioning.

Mental health. In the current study, fewer physiological stressors, greater satisfaction with performance of ADL, and less self-health management significantly correlated with greater overall mental health. Confidence with illness and treatment knowledge failed to influence overall mental health. Similar to the findings in the current study, Curtin et al. (2002) found that fewer physiological stressors were related to better overall mental health.

In the current study, greater satisfaction with physician support was significantly related to overall mental health. However, support from nurses, allied health professionals, and family failed to correlate with overall mental health. No comparable studies were identified in the literature reviewed that examined correlations between support and overall mental health.

In the current study, greater emotional well-being and less psychosocial distress were found to significantly correlate with better overall mental health. Again, very few comparable studies were identified from the literature. Similar to the current study's findings, Walters et al. (2002) found that participants who scored positive for depression had worse overall mental health.

In the current study, critical events exerted minimal effects on overall

mental health. The presence of negative illness events and negative self events were significantly correlated with poorer overall mental health. No comparable studies were found that examined the effects of critical events on overall mental health.

None of the demographic or medical risk factors were found to influence overall mental health. Similarly, Curtin et al. (2002), Diaz-Buxo et al. (2000) and Walters et al. (2002) failed to find any significant effect for age and gender on overall mental health. As well, Kutner et al. (2000) failed to document any relationship between urea reduction rate and albumin and overall mental health. In contrast, Kutner et al. found that increased age and increased hematocrit significantly correlated with better overall mental health.

Implications for the LESRD - H Model

The current study's findings provide partial support for the assumptions of the LESRD - H Model.

Study findings provide limited support for the direct effect of illness and treatment experience factors on adjustment to a new normal. Satisfaction with performance of ADL was the only consistent correlate of emotional well-being and psychosocial distress at both time periods. Counter to model projections frequency of physiological stressors and confidence with knowledge about the illness and treatment evidenced inconsistent effects, while self-health

management exerted no effect on adjustment. While it is acknowledged that the operational measures for these factors could be responsible for the findings, the current research base with this population provides limited insight into alternate factors.

In partial support of the LESRD - H model predictions, many of the illness and treatment experience factors were significant correlates of overall physical and mental health. Frequency of physiological stressors and satisfaction with performance of ADL were significant correlates of overall physical and mental health. Counter to model projections, self-health management only correlated with overall mental health, and knowledge confidence failed to correlate with either overall physical or mental health.

The limited influence of social support variables on adjustment and HRQOL was also counter to model projections. As expected, satisfaction with physician support correlated with emotional well-being, while satisfaction with nursing support correlated with psychosocial distress. Counter to model expectations, satisfaction with nursing and family supports depicted inconsistent relationships with emotional well-being, while satisfaction with physician and family supports depicted inconsistent relationships with psychosocial distress. As well, satisfaction with allied health professional support failed to significantly correlate with either emotional well-being or psychosocial distress. Significantly, only satisfaction with physician support was found to correlate with overall mental

health. Obviously, more research studies, using similar and different operational measures, are needed to examine the importance of informal and formal supports for adjustment and HRQOL.

The model assumption that adjustment variables would have a stronger effect on overall physical and mental health than either experience or support variables was partially supported. As well, study findings suggest that emotional well-being and psychosocial distress have a greater impact on mental than physical health.

Although critical events were found to exert minimal effects on adjustment and HRQOL, all of the correlations were in line with model projections (i.e., improvements in adjustment and HRQOL with positive events, and declines with negative events). Finally, as predicted by the model, demographic and medical risk factors exerted minimal effects on adjustment and HRQOL.

Summary

The current study investigated how individuals on hemodialysis perceived the illness and treatment experiences, social support, and adjustment to a new normal across two time periods. In addition, the study examined aspects of HRQOL (i.e., physical and mental health) at follow-up. A secondary focus was to determine what factors exerted the greatest influence on adjustment and whether these factors changed over time. Consideration was also given to factors

influencing HRQOL. Finally, the influence of select demographics and medical risk factors on adjustment and HRQOL was also examined. The LESRD-H model was used as the conceptual framework for the study.

For the most part, the findings in the current study were supported by findings from the literature. The findings also provide partial support for the assumptions in the LESRD-H model. Partial support is provided for the influence of illness and treatment experiences and social supports on adjustment. The findings support the assumption that aspects of adjustment exert the greatest effect on quality outcomes.

CHAPTER 6

Limitations and Implications

The findings from the current study have limitations and implications. The first section presents an overview of the limitations. The final section summarizes the implications for nursing practice, research, and education.

Limitations

The use of a non-probability convenience sample from four sites in the same province limits the generalizability of study findings to the hemodialysis population. As well, the loss of participants at follow-up contributes to the small sample in the current study. The use of self-report assessment tools without qualifying them with corroborating evidence (e.g., data from health care providers, family, etc.) is another limitation of the current study. Despite this, the repeated measures design increases the credibility of the results. As well, data were collected while participants were undergoing hemodialysis. The close proximity of participants with fellow patients, visitors, and the dialysis staff, and the background noise in the dialysis unit may have caused distractions and influenced responses provided. The significance of the study findings may be a function of the short time period (i.e., 6 to 9 months) between data collections, therefore, a longer time period may have been necessary to determine the sensitivity of the PPHS in detecting changes over time. A final limitation is

related to the PPHS. The instrument is still in its testing stage and will require further validation in a larger sample.

Implications

The findings have considerable implications for nursing practice, research, and education. Each will be addressed separately.

Practice

The findings from the current study suggest that participants were generally positive about the illness and treatment experience at both time periods. The most problematic areas of the illness and treatment experience were physiological stressors and satisfaction with performance of ADL. The areas influencing intermediary (i.e., adjustment) and quality outcomes (i.e., physical and mental health) may, for the most part, be modifiable with appropriate ongoing nursing interventions. Nurses working in the area of hemodialysis need to understand the effects that these stressors may have on patients. There is a need to perform ongoing, in-depth nursing assessments and to implement appropriate interventions targeted at decreasing physiological stressors and increasing participation in self-care ADL. These interventions may be essential in facilitating adjustment and improving client outcomes in the dialysis population.

There is also support in the literature for a relationship between knowledge and self-health management and adjustment. Nurses need to assess patients' and families' satisfaction and confidence with illness and treatment knowledge. This is a prerequisite step to the provision of timely and appropriate information. As well, there is a need to include strategies that promote self-health management that may lead to improved adjustment and quality outcomes.

Participants in the current study were quite satisfied with their formal and informal social support networks. While there was a positive association between support from nurses and emotional well-being at baseline, this relationship disappeared at follow-up. Support from nurses was not associated with overall physical and mental health. Nurses need to concentrate on ways to increase their influence on the emotional well-being, and overall physical and mental health of hemodialysis patients. While it is acknowledged that physicians play an important role in adjustment, the literature suggests that an interdisciplinary, collaborative approach to care may be a factor in facilitating positive quality outcomes in the hemodialysis population.

The literature supports the role of family in facilitating adjustment to ESRD and hemodialysis. The findings in the current study suggest that family support exerted minimal, and inconsistent effects, on adjustment, and was not related to the overall physical and mental health of the patient. Nurses need to understand

the impact of illness and treatment on not only the patient but also his or her family. Ongoing assessments of patients' support systems and the implementation of education programs aimed at developing coping strategies for both patients and family members may improve adjustment.

The findings in the current study suggest that participants had high levels of emotional well-being, but moderate levels of psychosocial distress. Nursing assessments should focus on key aspects of emotional well-being and psychosocial distress. Interventions to increase well-being and decrease distress are paramount to effective adjustment and acceptance of illness and treatment.

There is some support in the literature for the association of select medical risk factors on outcomes in the hemodialysis population. While medical risk factors (i.e., biochemical parameters) exerted minimal effects on adjustment variables and overall physical and mental health in the current study, there may be a need for nurses to provide ongoing patient and family education that reinforces the importance of adequate nutrition.

Research

This study has implications for further nursing research. The current study provided only partial support for the LESRD-H model. While the current study examined the direct effects among variables, further research using the model

with a larger, more diverse population is in progress. The national study will investigate the interactive effects among study variables by path analysis. There is a need to incorporate the PPHS into clinical research that focuses on more frequent measures over longer periods of time in order to document its usefulness as a monitoring tool for nurses. In addition, it would be beneficial to use a disease specific instrument to complement the generic instrument when examining quality outcomes.

There is an opportunity for nursing intervention studies. Studies focussing on decreasing physiological stressors and areas of psychosocial distress (e.g., decreasing fears, worries and uncertainties related to illness and treatment, promoting independence, etc.), and enhancing emotional well-being (e.g., ensuring a conducive dialysis environment, providing personalized care, etc.) that may affect outcome (i.e., adjustment) is needed.

While qualitative studies reinforce the importance of self-health management, performance of ADL, and knowledge in facilitating adjustment, it is questionable whether the items on the PPHS are actually asking the correct questions. Therefore, further refinement of the items on the PPHS is required.

The qualitative literature provides support for the importance of nurses in promoting acceptance and adjustment to illness and treatment. It would be beneficial to explore with nurses their understanding of how they perceive patients on hemodialysis adjust and cope with the rigorous and complex

treatment regimes, and the reliance on technology.

Education

Research findings related to chronic illness should be incorporated into nursing curricula to make future nurses aware of the effects of chronic illness on the individual and the family. Advances in technology and an aging population will mean more complex illness and treatment regimes. Consequently, nurses will need to be prepared with a basic understanding of chronic illness and what impact it has on the client and the family. Incorporation of evidence based research into nursing education curriculum is essential and will facilitate a research based practice model.

It is also imperative that nurses avail of continuing education providing research based programs. Information from these programs can be used to implement research findings that can contribute significantly to quality outcomes. Nurses working with the ESRD population should be encouraged to complete certification programs in nephrology nursing.

Summary

The results of this study indicate that participants were quite positive about their illness and treatment experience, social support, and adjustment to a new normal at both time periods. With the exception of self-health management and

support from family, no significant differences were observed between the variables across the time periods. The findings also indicated that participants were substantially impaired in overall physical health, however, they had excellent overall mental health. Individuals experiencing more positive illness and treatment experiences and greater adjustment to a new normal also reported better physical and mental functioning and well-being. Overall perceptions of social support failed to exert any influence on physical and mental functioning and well-being. The findings from the current study provide partial support for the LESRD-H Model and for the direct effects of factors on adjustment and HRQOL, however, it is apparent there are other factors that influence perceptions of ESRD and hemodialysis and HRQOL.

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Appendix A

Approval from Human Investigation Committee

Appendix B

Approval from Research Proposal Approval Committee
Health Care Corporation of St. John's

Appendix C

Consent Form

Faculty of Medicine, Memorial University of Newfoundland,
St. John's, Newfoundland A1B 3V6

CONSENT TO PARTICIPATE IN HEALTH CARE RESEARCH

RESEARCH STUDY TITLE: Living with Hemodialysis: Testing the Patient Perception of Hemodialysis Scale

INVESTIGATOR: Dr. Brendan Barrett
Telephone: 737-5157

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of the Study: You are being asked to participate in a research study of patients receiving hemodialysis treatment. Although many patients receive this type of treatment, very little is known about what the experience is really like for them. The purpose of this study is to develop a feasible method to measure and follow change in how people experience life on hemodialysis for end-stage renal disease. In doing so we hope to identify ways in which people view the meaning of their illness and/or treatment and aspects of their support system that may benefit from interventions such that nurses, doctors, and other health care providers may help patients achieve a positive sense of self with an improved quality of life.

Description of Procedures and Tests: You are being asked to respond to two questionnaires that will be read to you during one dialysis treatment. You will be asked questions about the history of your illness and treatment, the quality of your supports, for example, friends, family, nurses, doctors, etc., and how you have adapted to a "new self" while receiving hemodialysis treatment. With your permission further information will be taken from your health record, for example, cause of renal failure, presence of other illnesses, etc.

Duration of Participation: The first questionnaire will take approximately 60 minutes to complete and the second approximately 30 minutes.

Foreseeable Risks, Discomforts or Inconveniences: There are no expected risks from participating in this study. You may refuse to answer any questions which make you feel uncomfortable, and terminate the interview at any time. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the investigators and research nurses and assistants. Your name will not appear on the questionnaires. The inconvenience is associated with giving 60 minutes of your time for the first questionnaire and 30 minutes of your time for the second.

Benefits: You may not derive any direct benefits from participating in this study. However, the information that you provide may help nurses and physicians plan more appropriate care for you and others receiving hemodialysis treatment.

Other Information: Findings of this study will be available to you and health care professionals upon request. Findings may be published but you will not be identified. The investigator will be available during the study at all times should you have any questions or concerns about your continued participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I,_____, the undersigned, agree to my

participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

_____ _____

Signature of Participant Date

_____ _____

Signature of Witness Date

To the best of my ability, I have fully explained the nature of this study to the participant. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

_____ _____

Signature of Interviewer Date

_____

Phone Number

Appendix D

Baseline Personal Data Extraction Form

ID: _____

Personal Data Extraction Form

Dialysis Site: St. John's ____ HSC_____ SAGGH _____
Corner Brook _____
Montreal _____ Hamilton ____

Study #: _____

Preferred Language: _____

Age (years): _____ Date of Birth: _____
(d/m/yr.)

Sex:_____

Current Living Arrangements: Living Alone _____
Living with Spouse _____
Living with Parents _____
Living with Another Adult _____

Start Date of Dialysis: _____
(d/m/yr.)

Cause of End-stage Renal Disease:

Diabetes	_____
Glomerulonephritis/Autoimmune Diseases	_____
Renal Vascular Disease	_____
Polycystic Kidney Disease	_____
Congenital/Hereditary Renal Disease	_____
Other	_____

Presence of comorbid illness:	Yes	No
Heart Disease IHD	_____	_____
CHF	_____	_____
Stroke	_____	_____
Diabetes	_____	_____
Major Lung Problems	_____	_____
Cancer	_____	_____
Severe Arthritis	_____	_____
Amputation	_____	_____

Appendix E

Patient Perceptions of Hemodialysis Scale

PATIENT PERCEPTIONS OF HEMODIALYSIS SCALE

The following scale contains a list of items that reference events/situations that you may have experienced since the onset of kidney failure and starting hemodialysis. You are being asked to rate each item on a 5-point rating scales located in the columns to the right. In the first instance you are asked to indicate **'how often you feel this way'** (never, rarely, sometimes, often, or almost always). Finally, you are asked to indicate **'how satisfied, how confident, or how concerned are you'** (not at all, a little bit, moderately, quite a bit, considerably).

Rating Scales

How Often

Never	Rarely	Sometimes	Often	Almost Always
0	1	2	3	4

How Satisfied/How Concerned/How Confident

Not at all	A little bit	Moderately	Quite a bit	Extremely
0	1	2	3	4

1.	How confident are you that you understand the illness events that caused the loss of your kidney function?	0	1	2	3	4
2.	How concerned are you that your health will get worse regardless of what you or doctors do?	0	1	2	3	4
3.	How often do you experience breathing difficulties?	0	1	2	3	4
4.	How often do you feel tired and low on energy?	0	1	2	3	4
5.	How often are you bothered by walking short distances (e.g., tired feelings, breathing problems, etc.)?	0	1	2	3	4
6.	How confident are you that you understand why you need diet or fluid restrictions?	0	1	2	3	4
7.	How satisfied are you with the information that you have about the benefits/side-effects of dialysis?	0	1	2	3	4

8.	How often do you think about what could happen if you did not follow recommended diet and fluid restrictions?	0	1	2	3	4
9.	How often do you experience muscle cramps during or after dialysis?	0	1	2	3	4
10.	How often do you experience a drop in blood pressure during or after dialysis?	0	1	2	3	4
11.	How often do you experience itching due to your kidney disease?	0	1	2	3	4
12.	How often do you feel exhausted after dialysis?	0	1	2	3	4
13.	How often do you feel comfortable after dialysis (e.g., less breathing problems, less swelling, etc.)?	0	1	2	3	4
14.	How often do you feel that dialysis has improved the quality of your life?	0	1	2	3	4
15.	How confident are you about knowing what is required to have a kidney transplant (e.g., waiting period, reasons for not being placed on or coming off the wait-list, etc.)?	0	1	2	3	4
16.	How often do you follow recommended diet and fluid restrictions?	0	1	2	3	4
17.	How often do you pay attention to what nurses do during dialysis (e.g., saline for cramps, checking blood pressure, turning off heparin, etc.)?	0	1	2	3	4
18.	How often do you watch for problems that could occur during dialysis such as bleeding/clotting of access site, cramps, or changing blood pressure?	0	1	2	3	4
19.	How often do you inform the nurse about problems that occur during dialysis (i.e., feeling unwell, problems with access site, etc.)?	0	1	2	3	4
20.	How often does your family try to help you accept your illness and dialysis treatment requirements?	0	1	2	3	4
21.	How concerned are you about becoming too dependent on your family?	0	1	2	3	4

22.	How often do family members remind you about diet, fluid, or activity restrictions?	0	1	2	3	4
23.	How concerned are you about the impact of your illness and treatment on family members? (e.g., decreased social activities, dietary restrictions, time commitments with dialysis, etc.)	0	1	2	3	4
24.	How often do you do things to lessen the impact of your illness and treatment on family members?	0	1	2	3	4
25.	How often do you feel that your family is coping well with your illness and dialysis treatment requirements?	0	1	2	3	4
26.	How often do you experience delays in getting on dialysis or receiving scheduled treatment (e.g., turning off heparin, etc.)?	0	1	2	3	4
27.	How concerned are you that nurses may be too busy to pay attention to what is happening to you during dialysis?	0	1	2	3	4
28.	How satisfied are you with the overall quality of nursing care in the dialysis unit?	0	1	2	3	4
29.	How confident are you that nurses have the knowledge and abilities to know what to do if you became ill on dialysis?	0	1	2	3	4
30.	How satisfied are you with nurses willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
31.	How satisfied are you with the amount of time that nurses take to help you understand your illness and treatment requirements?	0	1	2	3	4
32.	How often do you feel that nurses try to promote a relaxed, family-like atmosphere on the dialysis unit?	0	1	2	3	4
33.	How satisfied are you with the comfort measures provided by nurses during dialysis (e.g., providing a blanket, pillow, refreshments, etc.)?	0	1	2	3	4
34.	How confident are you that dialysis doctors' have the necessary knowledge and abilities to monitor or deal with your overall physical needs?	0	1	2	3	4

35.	How satisfied are you with how quickly doctors respond to your needs when you are on dialysis?	0	1	2	3	4
36.	How satisfied are you with the quality of overall medical care in the dialysis unit?	0	1	2	3	4
37.	How satisfied are you with doctors willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
38.	How satisfied are you with the amount of time that doctors take to help you understand your illness and treatment requirements?	0	1	2	3	4
39.	How satisfied are you with the support provided by dialysis social workers to help you deal with illness or treatment-related problems?	0	1	2	3	4
40.	How satisfied are you with the information provided by the dietician about your diet?	0	1	2	3	4
41.	How often do you feel so frustrated with things that you would like to get off the machine and go home?	0	1	2	3	4
42.	How concerned are you for your personal safety while on dialysis (i.e., cluttered or messy environment, germs, etc.)?	0	1	2	3	4
43.	How concerned are you about voicing your needs to nurses or doctors due to the physical closeness of others during dialysis?	0	1	2	3	4
44.	How often are you upset by seeing others become suddenly ill (i.e., worried that it would happen to you)?	0	1	2	3	4
45.	How often do you dwell on your own health problems following the death of another patient?	0	1	2	3	4
46.	How often do you feel depressed (i.e., feeling down, fed-up, frustrated) about your illness and long-term treatment requirements?	0	1	2	3	4
47.	How satisfied are you with your ability to do household or other work activities?	0	1	2	3	4

48.	How often do you experience fears or worries about unexpected illness/dialysis events (e.g., sudden drop in blood pressure, clotting of access site, breathing problems due to too much fluid)?	0	1	2	3	4
49.	How often do you feel that depending on others makes you feel useless (i.e., self-esteem, self-worth)?	0	1	2	3	4
50.	How often do you feel distressed by the severity of your illness and the long-term treatment requirements (e.g., troubled, worried, upset, etc.)?	0	1	2	3	4
51.	How often do you feel stronger as a person because of your illness (i.e., discovery of inner strength, spiritual comfort, courage)?	0	1	2	3	4
52.	How often do you try to maintain a positive attitude towards dialysis?	0	1	2	3	4
53.	How often do you feel good about the 'special closeness' among patients during dialysis?	0	1	2	3	4
54.	How confident are you that you will come to terms with your illness?	0	1	2	3	4
55.	How often do you accept dialysis as something you have to do (i.e., scheduled appointment, part of weekly norm)?	0	1	2	3	4
56.	How often do you relax during dialysis?	0	1	2	3	4
57.	How often do you participate in recreational activities (e.g., travel, volunteer work, hobbies, etc.)?	0	1	2	3	4
58.	How satisfied are you with how well you have adjusted to the effects of dialysis (e.g., pain, restrictions, problems with access site, delays, machine functioning, drop in blood pressure)?	0	1	2	3	4
59.	How confident are you that you can manage the financial costs resulting from dialysis?	0	1	2	3	4
60.	How satisfied are you with the amount of quality time spent with family and friends?	0	1	2	3	4

61.	How confident are you that you are coping well with dialysis restrictions?	0	1	2	3	4
62.	How often do you feel that you have some control over the ups and downs of dialysis and the effects on your health and well-being?	0	1	2	3	4
63.	How often do you try to weigh the benefits/negatives of different treatment options before making a decision (e.g., home vs hemodialysis, transplant, counselling, time of day or days on dialysis, etc.)?	0	1	2	3	4
64.	How satisfied are you with the amount of self-care responsibilities that you are able to assume on a given day?	0	1	2	3	4

Appendix F

Medical Outcomes Study Short Form 36 (SF - 36)

SF-36 HEALTH SURVEY

This survey asks for your views about your health. This information will keep track of how you feel and how well you are able to do your usual activities. If you are unsure about how to anwer a question, plea give the best answer you can.

NOTE TO INTERVIEWER: For each question, place a check mark (✓) in the box corresponding to th subject's response.

1. In general, would you say your health is:

   - ☐ 1 Excellent
   - ☐ 2 Very good
   - ☐ 3 Good
   - ☐ 4 Fair
   - ☐ 5 Poor

2. ***Compared to one year ago***, how would you rate your health in general ***now***?

   - ☐ 1 Much better now than one year ago
   - ☐ 2 Somewhat better now than one year ago
   - ☐ 3 About the same as one year ago
   - ☐ 4 Somewhat worse now than one year ago
   - ☐ 5 Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does ***your health now limit you*** in these activities? If so, how much?

	ACTIVITIES	Yes, Limited A Lot 1	Yes, Limited A Little 2	No, Not Limited At All 3
a	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports			
b	**Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
c	Lifting or carrying groceries			
d	Climbing several flights of stairs			
e	Climbing one flight of stairs			
f	Bending, kneeling, or stooping			
g	Walking more than a kilometre			
h	Walking several blocks			
i	Walking one block			
j	Bathing or dressing yourself			

SF-36 HEALTH SURVEY (CONT'D.)

4. During the ***past 4 weeks***, have you had any of the following problems with your work or other regular daily activities ***as a result of your physical health*** ?

		Yes 1	No 2
a	Cut down on the **amount of time** you spent on work or other activities		
b	**Accomplished less** than you would like		
c	Were limited in the **kind** of work or other activities		
d	Had **difficulty** performing the work or other activities (for example, it took extra effort)		

5. During the ***past 4 weeks***, have you had any of the following problems with your work or other regular daily activities ***as a result of any emotional problems*** (such as feeling depressed or anxious)?

		Yes 1	No 2
a	Cut down the **amount of time** you spent on work or other activities		
b	**Accomplished less** than you would like		
c	Didn't do work or other activities as **carefully** as usual		

6. During the ***past 4 weeks***, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

- ☐ 1 Not at all
- ☐ 2 Slightly
- ☐ 3 Moderately
- ☐ 4 Quite a bit
- ☐ 5 Extremely

7. How much ***bodily*** pain have you had during the ***past 4 weeks*** ?

- ☐ 1 None
- ☐ 2 Very mild
- ☐ 3 Mild
- ☐ 4 Moderate
- ☐ 5 Severe
- ☐ 6 Very Severe

8. During the ***past 4 weeks***, how much did ***pain*** interfere with your normal work (including both work outside the home and housework)?

- ☐ 1 Not at all
- ☐ 2 A little bit
- ☐ 3 Moderately
- ☐ 4 Quite a bit
- ☐ 5 Extremely

SF-36 HEALTH SURVEY (CONT'D.)

9. These questions are about how you feel and how things have been with you ***during the past 4 weeks***. For ea question, please give the one answer that comes closest to the way you have been feeling.

	How much of the time during the past 4 weeks ...	All of the Time 1	Most of the Time 2	A Good Bit of the Time 3	Some of the Time 4	A Little of the Time 5	None of the Time 6
a	Did you feel full of pep?						
b	Have you been a very nervous person?						
c	Have you felt so down in the dumps that nothing could cheer you up?						
d	Have you felt calm and peaceful?						
e	Did you have a lot of energy?						
f	Have you felt downhearted and blue?						
g	Did you feel worn out?						
h	Have you been a happy person?						
i	Did you feel tired?						

10. During the ***past 4 weeks***, how much of the time has your ***physical health or emotional problems*** interferec with your social activities (like visiting with friends, relatives, etc.)?

- ☐ 1 All of the time
- ☐ 2 Most of the time
- ☐ 3 Some of the time
- ☐ 4 A little of the time
- ☐ 5 None of the time

11. How ***TRUE*** or ***FALSE*** is ***each*** of the following statements for you?

		Definitely True 1	Mostly True 2	Don't Know 3	Mostly False 4	Definit False 5
a	I seem to get sick a little easier than other people					
b	I am as healthy as anybody I know					
c	I expect my health to get worse					
d	My health is excellent					

Appendix G

Follow-up Personal Data Extraction Form and Critical Events Checklist

Data Abstraction Form & Critical Events Checklist

Date (6 months Follow-up)
Date: _____
(d/m/yr)

Average of the last three months:
Albumin Level:
Hgb:
Percent reduction in urea:
Phosphate:

Hospitalization past 6 months:

Yes ___ No ___
Number of admissions: _____
Reason (s) for admission: _____
_____
_____
_____

Co-morbid Diseases:
Yes ___ No ___

	Yes	No
Heart Failure symptoms on strenuous or prolonged activity, or prior heart failure		
Heart failure on ordinary activity, at rest, or recurrent admissions in heart failure		
New onset or stable angina or myocardial infarct > 6 mo previously		
Unstable angina or myocardial infarct < 6 months previously		
Treated arrhthymia present		
Gangrene, inoperable or surgery for peripheral vascular disease < 6 months previously		
Diabetes		
Current malignancy		
Major lung problems		
Stroke with disability		

Critical Events Checklist

I am interested in any significant experiences that you may have had within the past six months. I have a list of events/situations that were identified by a group of patients receiving hemodialysis. I would like for you to take some time to reflect upon these events/situations and indicate whether or not you have experienced any of them since our last interview with you.

		Yes	No
I	**Illness Related - Negative**		
1.	**Loss of renal function** (e.g., no/minimal urine output, increased time on dialysis).		
2.	**Loss of alternate treatment modality** (e.g., transplant not an option, failure of home dialysis).		
3.	**Unpredictable illness course** (i.e., variable level of physical functioning)		
4.	**Declining health status and well-being** (e.g., negative effects of comorbid illness and/ or acute illness episodes - walking/breathing difficulties, reduced energy, insomnia, itching, leg cramps, social restrictions).		
5.	**Reduced desire/motivation to following recommended lifestyle changes** (i.e., diet modifications, fluid/exercise/work restrictions).		
II	**Illness Related - Positive**		
1.	**Improved renal function** (e.g., increased urine output, reduced dialysis time).		
2.	**Availability of Desired alternate treatment modality** (e.g., transplant, home dialysis).		
3.	**Predictable illness course** (i.e., stable physical functioning)		

		Yes	No
4.	**Improved health status and well-being** (e.g., positive effects from dialysis, no/minimal effects of comorbid illness, absence of acute illness episodes, increased stamina, etc.).		
5.	**Increased desire/motivation to following recommended lifestyle changes** (i.e., diet modifications, fluid/exercise/work restrictions) .		
III	**Treatment Related - Negative**		
1.	**Problems with dialysis access site**		
2.	**Travel** (e.g., arrangements, distance, inconvenience)		
3.	**Length of time spent on dialysis** (e.g., prescribed dialysis time, delays with initiating treatment, delays post-dialysis)		
4.	**Unwell feelings during dialysis** (i.e., due to cramping, nausea, unstable blood pressure, etc.)		
5.	**Decreased physical functioning or no perceived improvement in physical health after dialysis** (e.g., exhaustion, breathing difficulties, headaches, etc.).		
IV	**Treatment Related - Positive**		
1.	**Well-functioning dialysis access site**		
2.	**Absence of travel worries/concerns**		
3.	**Length of time on dialysis** (e.g., prescribed dialysis time, no delays with initiating treatment, no delays post-dialysis)		
4.	**Good feelings during dialysis** (i.e., restful, no problems, etc.)		

		Yes	No
5.	**Increased physical functioning or sense of normalcy after dialysis** (e.g., less breathing problems, comfortable/restful feelings, high energy levels, etc.).		
V	**Quality of Supports - Negative**		
1.	**Loss of fellow patients**		
2.	**Loss of family**		
3.	**Loss of friends and/or support network**		
4.	**Reduced trust and confidence in nurses**		
5.	**Reduced trust and confidence in physicians**		
6.	**Dissatisfaction with dialysis environment (e. g., lack of privacy, cluttered space, presence of acutely ill or dying patients, etc.)**		
VI	**Quality of Supports - Positive**		
1.	**Good rapport with fellow patients**		
2.	**Strong family supports**		
3.	**Positive social environment (i.e., friendships, colleagues, leisure activities)**		
4.	**Trust and confidence in nurses**		
5.	**Trust and confidence in physicians**		
6.	**Satisfied with dialysis environment (e. g., level of privacy, space, etc.)**		

		Yes	No
VII	**Loss of "Old Self" - Negative**		
1.	**Reduced self-worth/self-esteem**		
2.	**Feeling of loss control of life events/ environment**		
3.	**Loss of independence**		
4.	**Dissatisfied with level of social activities**		
5.	**Potential/actual threats to financial security**		
6.	**Negative attitude towards illness/treatment**		
7.	**Uncertainty and stress associated with health and quality of life**		
8.	**Feelings of hopelessness**		
VIII	**Adapting to New Normal - Positive**		
1.	**Increased self-worth/self-esteem**		
2.	**Feeling in control of life events/environment**		
3.	**Independent living**		
4.	**Satisfied with level of participation in social activities**		
5.	**No/minimal impact on financial security**		
6.	**Positive attitude towards illness/treatment**		
7.	**Satisfied with health and quality of life**		
8.	**Feeling hopeful**		